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PED'AGOGICKÁ FAKULTA

Diplomová práce

A case study on Group Homes

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Date: 31.08.06

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(GEETHA MURALIDHARAN)

ABSTRACT

This case study is on community based alternatives namely group homes for people with intellectual disabilities in Czech Republic. It focuses on 2 different service providers namely the social workers and specialist in the field of disabilities and the parents who wanted to provide their wards a good living condition for the rest of their life. This qualitative cum quantitative study has used interview, observation and standardized choice questionnaire (Stancliff and Parmenter, 1999) as the tools for data collection. The study involved people with intellectual disabilities (mild and moderate) who lived in the group homes and one staff from each group home. Because of the time constrain and language barrier all the stake holders could not be involved. The findings showed that both the settings were unique in their own way and they proved to be a good model for a group home, where the welfare of the residents were given priority and all the plans were worked around the residents irrespective of their ability and involvement. Efforts were made not to minimize assistance, but rather to minimize the creation of dependence. Both the group homes followed the principle of normalisation and advocated the maximization of individual's abilities and choices. This study was carried out keeping in mind how similar kind of group homes can be planned and set in India for people with intellectual disabilities, where disability issues are in the process of getting legalized which is very similar to the situation in Czech Republic after the collapse of the communist regime in 1989.

Keywords:

Institutionalisation, Deinstitutionalisation, Normalisation, Community based alternatives, Group homes, Quality of Life, Choice, and Intellectual disability.

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CHAPTER 1

"It is not until we recognise the person with a disability as a citizen, a member of society who belongs to his family and his local community, community living becomes logical and natural"

- (Ericsson, 2005).

1. INTRODUCTION

People with intellectual disabilities have the same rights as others to experience a fulfilling and meaningful life. In order to enable disabled people to live, with the necessary support, in the community and to have the same opportunities to participate in society as everyone else, it is imperative that concrete steps are taken to shift the provision of care from closed institutions to community-based services. This way, persons with disabilities will avoid having their personalities shaped by living in an institution. Being part of the surrounding community will lead to new relationships and experiences. Institutionalisation locks away the human spirit and can leave people vulnerable to violence and exploitation. Deinstitutionalisation offers hope of allowing people an opportunity to be part of their community (Gerard Quinn, 2006). Steven Eidelman from the University of Delaware's Disabilities Centre recommends that the term de-institutionalisation be replaced with "developing community capacity for all people". If this happens during the course of time, then quality of life would become an integral part of all the measures that are taken towards setting up community based alternatives (Working Together for Community Living- Report from the Right to live in the Community Seminar on 17 May 2006).

Many people with disabilities choose to live with their families for a variety of reasons. Economics and personal safety are primary factors. Family and friends can be expected to know the individual needs of a disabled family member better than anyone else, and therefore may be in the best position to help. Personal safety is better assured, as well as dependability of care and support. However, insecurity exists about the longevity of this type of arrangement. Many parents live in fear of what will happen to their child with disability when

they are no longer able to care for him or her. Typically friends or relatives step in to continue providing care. This situation brings to discussion about community based alternatives for people with disabilities, when their support system ceases to exist in particular for people with intellectual disabilities.

Both the developed and developing countries are striving towards a better social and citizenship model, focusing more on improving the 'quality of life ' of people with disabilities in all sectors of life namely, education, vocation, employment and living. Social integration and self actualization of people with disabilities is gaining impetus all over the world. But we can see the developed and developing countries responding to the same at different levels, although their motives are the same, which is, community integration. The reason for this being that the disability movement has come a long way in the developed countries when compared to the developing countries.

When we look back at the history we can find that the Disability movement with its charity and medical model started in the developed countries in the 19th century and paved way to the construction of institutions during the late 19th centuries. Institutions were thought to be the resort for people with disabilities, where they could be cured and given an opportunity to live a normal life. Simultaneously during the same period the developing countries were trying hard to provide services to their disabled population. But they lacked the money to construct institutions. So during the early 20th century when the developed countries were campaigning for deinstitutionalisation and trying to bring into action the principal of normalisation through community based alternatives (CBA) and community-living, the developing countries started the service of community based rehabilitation (CBR) for their disabled population. Through these community based rehabilitation programme the developing countries integrated the services for their disabled population directly into the community. Thereby no separate measures were taken for building institutions for the disabled population. Even if there were institutions they were very few and were run by government and were similar to those of hospitals.

Lately, both the CBR in developing countries and CBA in developed countries are working towards improving the 'quality of life' of people with disabilities. Although the developed countries are far ahead in the program of community based alternatives lately India, Japan (Disability Information Resources-Japan) and many other developing countries are adopting the principal of Normalisation and are opening community based alternatives like group homes for people with disabilities in their countries, in particular for people with intellectual disabilities. In India we have community Based Rehabilitation programs as inter-dependence is the 'way of life'. Community based rehabilitation is a more welcoming goal in countries where there is strong sense for community, inter-dependence or living together. According to Lysack, 1994 as cited in Rodgers (1998), the entire community is the target of CBR programs; the CBR model is one of community development or community partnership.

1.1 India and Disability

India with a population of more than a billion people only 5 to 10% of people with disabilities have access to or are reached by any kind of rehabilitation or social service. This means that 40 - 45 million disabled people have no access to services at all. The proportion of rural and urban population is 75% and 25% respectively but most rehabilitation services are to be found in the large cities. The prevalence of disability is higher in rural areas where the bulk of the population lives (Access to Rehabilitation Services in India, 2005) and support in rural areas is particularly poor. The main reason for this is that adequately trained human resources are not available. Moreover, in a country with many competing priorities, disability receives a low priority (Kundu 2005). In India the problem is made more complex by the fact that, for most part the disabled persons are also usually extremely poor people. They often live in areas where medical and other related services are scarce, or even totally absent. When they do receive medical attention, if they receive it at all, the impairment may have become irreversible.

1.2 India and Disability Acts

In India, issues regarding disabilities come under the Ministry of social justice and empowerment. The constitution of India ensures equality, freedom, justice and dignity of all individuals and implicitly mandates an inclusive society for all including persons with

disabilities. The earlier emphasis on medical rehabilitation has now been replaced by an emphasis on social rehabilitation. There has been an increasing recognition of abilities of persons with disabilities and emphasis on mainstreaming them in the society based on their capabilities. The Government of India has enacted three legislations for persons with disabilities viz.

(i) Persons with Disability (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, which provides for education, employment, creation of barrier free environment, social security, etc.

(ii) National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability Act, 1999 has provisions for legal guardianship of the four categories and creation of enabling environment for as much independent living as possible.

(iii) Rehabilitation Council of India Act, 1992 deals with the development of manpower for providing rehabilitation services.

(National policy for persons with disabilities, Disability India Net)

According to the Census 2001, there are 2.19 crore persons with disabilities in India who constitute 2.13 percent of the total population. Ali Baquer, cited in 'Disability Issues' that at least one out of every 10 people in India suffers from some form of physical, sensory, or mental disability.

1.3 India and community based alternatives

India's disability-related policies are moving away from medical rehabilitation toward a more CBR approach for the self-sufficiency and improvement of Person with Disability (PWD) status through vocational training and education. There is currently no formal initiative in India for the Independent Living Movement (Asia-Pacific Development Center on Disability, 2005) other than the 'SAMARTH' "Centre Based Scheme (CBS)" which has been in effect from the financial year 2005-06. This scheme is for Residential Services, both Short Term (Respite Care) and Long Term (Prolonged Stay) and is launched by National trust ("Act 44 of 1999" of National Trust). In India, although the present situation regarding the residential services for people with disabilities look to be in dismay(Natarajan, Chair Person of National Trust, e-mail dated 17th July 2006, see appendices), non-government organisations are

working out their own models of group home and independent living for people with disabilities in particular for people with intellectual disabilities. Presently, in India 2 projects that are running group homes or residential services for people with intellectual disabilities are Swayamkrushi in Hyderabad, established in 1991 and The Camphill community in Bangalore established by 'Friends of Camp hill India'(A residential community with mentally disabled adult).

1.4 About my study ...

Although this study reviews the history of residential institutions followed by deinstitutionalisation and setting up of community based alternatives (supported living, group homes/independent living) in many parts of Europe, the focus is on Czech Republic. An effort has been made to understand the impact of communist regime on people with disabilities and to study the history of institutionalisation in Czech Republic and how Community Based alternatives are currently being launched after the collapse of the communist rule in 1989. The study is based on two group homes, one run by service providers who are specialists and social workers and another one initiated by parents for their wards with disabilities. The study is based on the report on Residential institutions in Europe as documented in 'Included in society'.

The study conducted by the project "Included in Society", a first attempt to compare institutions for disabled people in different European countries has made me think about the quality of community based alternatives for people with disabilities. In particular my focus is on people with developmental disabilities as they are dependent cognitively in making decisions about their day to day living. Personally I believe making choices and deciding for one self even on small daily matters and their involvement in the running of home and having their own personal space and relationships with others improves the self-esteem of an individual. This for sure would bring about a major difference to the life of people with intellectual disabilities by improving their 'quality of life'. The study 'Included in society' shows clearly that large residential institutions, often located in isolated places, segregate their residents from the community and from social life, which deprived them from the richness of living together. Furthermore, it provides evidence of situations in which the human rights of

residents in large institutions are often violated. Large residential institutions segregate residents from the community and normal social life, which add to their disability. Disabled people in such institutions are usually the most "invisible" citizens.

Residential institutions were a central part of social policy in most of Central and Eastern Europe and the former Soviet Union, though the use of residential institutions and the impact they had on their residents varied. Residential institutions were more than merely housing for marginalized populations. They served a dual role of social protection and social regulation (Tobis, 2000). But lately, researches have found that in Western Europe and in the United States community-based services are less expensive than residential care (institutions) and far better for vulnerable individuals. Similar findings have emerged from new community-based service programs developed by governments within the region in collaboration with the World Bank, European Union, United Nations Children's Fund, Open Society Institute, Save the Children, Caritas, and other organizations. Over the past 10 years community-based social services have developed very slowly in Central and Eastern Europe and the former Soviet Union (Tobis, 2000).

Over the years all manners of variables have been included in studies of what constitutes quality and what the benefits of one type of residential care are when compared with another. These variables have included studying the effects of the residential setting on changes in behaviour, participation in the community, contact with staff, participation in domestic cores and choice (Simmons & Watson, 1999 as cited in Gates, 2003, pg. 87). This study on 2 group homes focuses on degree of choice exercised by the residents on a daily basis, participation of the residents in the domestic chores and in the running of the group home in partnership with the service providers. But unless we define what a home is, we can never move further in setting up a group home or any community based alternatives with high standards of quality of life. If this doesn't happen, it is going to be like setting up another institution. Home is, for many of us, more than just a physical place. The meanings of a true home encompass social and emotional experiences as well as reflecting personal values and standards. Annison's paper (2000) comments on the (mis)application of the term *home* to living facilities for people with intellectual disability and reminds us that residences physically located in the

community do not necessarily provide a "true" home for the people who live in them. The shift in policy from residential provision in institutions to provision in the community has been accompanied by far greater emphasis on the quality of services provided (Perry and Felce, 2003). Research on quality in residential settings has highlighted marked variation in both the processes underlying services and the outcomes experienced by residents (Emerson & Hatton 1994 as cited in Perry and Felce, 2003). To date, most research has reported on resident outcomes in terms of the objective life conditions which resident's experience. For a variety of reasons, evidence of residents' subjective experiences of their residential living situation is sparse. In Britain and other countries, the expansion of community provision has been paralleled by increased interest in the conceptualization and measurement of quality of life (QoL). The term 'quality of life' is generally considered to encompass the breadth of life experience (Perry and Felce, 2003). One aspect of this study is to measure the degree of choice exercised by the residents of the 2 group homes using a standardized choice questionnaire framed by Stancliffe and Parmenter, 1999. This is a client cum proxy questionnaire. In this study the residents' voices were heard as they participated in filling the questionnaire, which brought out the subjective aspect of the residents.

I agree to Ericssons (2005) comments, that, it is the person with a disability who must be allowed to answer the question as to what sort of life he or she wants to live. Ericsson (2005) emphasizes that this must be the starting point with the role of disability services being to contribute to the provision of that quality of life, in terms of providing housing choices, daytime activity choices, choices over everyday life, relationships and personal development and providing a opportunity for the expression of personal needs, requests and opinions.

I believe that the main purpose of setting up group homes as an alternative to residential institution is to secure community based alternatives as an essential component of regaining the citizenship rights of disabled people. While doing so, personally I believe that if adults with disabilities are offered support in a group home to live like other people they will develop a personal daily rhythm as regards getting up in the morning, eating at regular hours, having work hours, leisure time, and bed time. In addition, this will lead to a normal weekly routine with opportunities to participate in cultural or other activities in one's neighborhood,

depending on one's individual interests which would improve their quality of life and provide richness to their life. Most of the people with developmental disabilities, possess limited abilities and need support in order to experience and participate in different activities and to make decisions about what they would like or prefer? Here the role of the service provider becomes very important because they need to support and encourage the residence to lead a life which is very much similar to their non-disabled friends. So I would like to observe how the service providers and parents work towards this.

For people with developmental disabilities, decision making is an area that needs guidance. When talking about community alternative services like group homes, I wonder how much opportunity or importance is given towards the development of the skills of decision making. As it is believed that, this alone can bring about a difference in the life of a person with developmental disability. Through this the person is made responsible for every single decision he/she takes, which is the central focus for independent living and citizenship model. People with high dependency needs cannot necessarily participate actively in all areas of life, yet they still have a right to non discrimination and freedom of choice as to how and where they live, to a good quality of life and to be socially included. Are the community based alternatives, namely the group homes for people with developmental disabilities considering these goals as their priority? In my study I have made an effort to reason out this issue regarding people with intellectual disabilities living in group homes.

1.5 About myself...

I have been working in the field of disabilities in India for the last four years as a special educator and as a disability activist in a non-government organisation in South India, which works for people with multiple disabilities. We run many projects namely the early intervention, family based rehabilitation, Center for special Education, adult program, man power training, community based rehabilitation and advocacy cell. The adult program is planning to launch a group home for young adults with multiple disabilities. The experience I am going to gather through my study here in Czech Republic will help me and my organisation to initiate the project on Group home with the Principal of Normalisation as its basis. By doing this study, I am sure I will be aware of the hurdles faced by non-government

organisations and people with disabilities in the process of deinstitutionalisation and the construction of community based alternatives in particular Czech Republic and all over Europe too.

CHAPTER 2

2. REVIEW OF LITERATURE

2.1 Introduction

People with intellectual disabilities represent one of the most disadvantaged social groups in European countries. The pervasive nature of intellectual disabilities creates very high levels of need for assistance often throughout every aspect of the individual's existence and over the whole of the person's life. Traditional patterns of care have been heavily based on institutions, which tend to segregate and isolate people from the main stream of society (Beadle-Brown et al. 2003). Before going further, the important key areas that will be addressed in this study would be demystification of the terms namely intellectual disability, mental retardation and learning disability, followed by the brief history on institutionalisation, process of deinstitutionalisation and concept of normalisation, importance of community based alternatives with focus on group homes for people with intellectual disabilities.

Residential homes have been an active site for the struggle for citizenship rights. Miller and Gwyenne as cited in Finkelstein(1991) maintained that 'by the very fact of committing people to institutions of this type, society is defining them as, in effect, *socially dead*, then the essential task to be carried out is to help the inmates make their transition from social death to physical death'. So, in the words of the disabled, once a disabled person had entered the institution 'society has effectively washed its hands of the inmates as significant social beings'. Residential homes were an important symptom of public acceptance that disability means social death (Finkelstein, 1991). To voice against this social death of people with disabilities, high quality community-based services must be established upon the core values of equal citizenship and social inclusion. Arising from existing human rights instruments, five key principles for positive change can assist and underpin such work: respect, choice, participation, independence, as well as regional/local responsibility for disabled citizens (Included in society). However, 'barriers to effecting positive change are more complex in the countries of CEE' (Klein & Parker, 2003, p. 16) due at least partly to the transition from state-domination to more open societies (Barbara & Siska, 2006).

Over the past two centuries, the government policy of many countries has been to place disabled people in large institutions, often situated in remote parts of the country so that residents have little or no contact with the outside world. The individuals who have been most affected by these policies are people with intellectual disabilities, Autistic Spectrum Disorders, those enduring mental health problems and those with complex dependency needs. Disabled people in residential institutions are usually the most "invisible" citizens. There is often great ignorance about their practical living conditions and how their needs and rights can be matched with those conditions. Scientific research has demonstrated that such institutions are not able to deliver the same quality of life for their residents as community-based alternatives (Included in society).

The first social movement was deinstitutionalization, an attempt to move people, primarily those with developmental disabilities, out of institutions and back into their home communities. This movement was led by providers and parents of people with developmental disabilities and was based on the principle of "normalization" developed by Wolf Wolfensberger, a sociologist from Canada. His theory was that people with developmental disabilities should live in the most "normal" setting possible if they were to be expected to behave "normally." (Wolfensberger, 1972 as cited in McDonald, G., & Oxford, M. (No date)).

Introduction to the concept of community care/community living and the principles of normalisation, resulted as a result of distillation of significant ideas, attitudes and social movements in the post-war years. Firstly the recognition of the inequalities faced by disabled people led to the formation of a number of human and civil rights movements and this subsequently led to the introduction of a number of policies including the European Convention on Human Rights (1950). Secondly, at this time there was a shift away from the 'problem' being one of a person's disability, to being the result of the person's physical environment. Tizard & O'Connor (1952) and Clarke & Clarke's (1959) work demonstrated that large number of individuals living in institutions at that time had the intellectual and social capabilities to sustain themselves in the community, and that the institutional life did little to support personal development. Thirdly the disclosure of Howle report, 1969, regarding the sub-normal conditions of the services in institutions, fuelled a number of social

activist group that deplored the standards of institutions and their blatant disregard of the human rights of both residents and their families (National council of civil Liberties, 1951.(Gates, 2003, pg. 53-54). This lead to the setting up of community based alternatives.

2.2 Community based alternatives

Community-based alternative services provide a means of reintegrating people with intellectual disabilities into the community as well as preventing the need for institutionalization in the first place (Barbara & Siska, 2006). In order to enable disabled people to live, with the necessary support, in the community and to have the same opportunities to participate in society as everyone else, it is imperative that concrete steps are taken to shift the provision of care from closed institutions to community-based services. In some countries in Central and Eastern Europe, community-based services exist only as small and isolated programs (Included in society).

In order to exercise their rights and participate fully in the society, people with disabilities need to have access to comprehensive, quality community-based services. This means living independently in the community, with the family or in small group homes or individual housing, with adequate support based on each person's individual needs. It also means having access to education and employment, as well as social and cultural life of the community. It means having choices and living with dignity. To ensure that community-based services are provided on the basis of individual needs, people with disabilities must be involved in their development, together with other stakeholders. It is important that the planning, provision and review of community-based services are founded on the values of equal citizenship and social inclusion, as well as the principles for positive change (European Coalition for community Living). This is often referred to as supported living.

Supported living represents a way of constructing community-based services that takes services to people's own homes, and then develops around them the kinds of support they will need to live as independently as possible(Gates, 2003, pg.85). It is important to remember that supported living does not imply that all people with learning disabilities no longer require the support of qualified and highly skilled assistance, on the other hand simply to place people

in residential settings without appropriate support systems in place might be both dangerous and self-defeating. Within this type of residential alternative a range of options might include rented or leased accommodation, or ownership of one's own property. In a sense supported living might be a direct consequence of person-centered planning. This is because the type of residential alternative offered to people is constructed around their needs, wishes and aspirations (Gates, 2003, pg.85). Group homes provide combined accommodation and support services to people living in the community (Gates, 2003, pg. 533). There now exists sufficient and overwhelming evidence that smaller more community-oriented residential services have brought about significant improvements for people with learning disabilities, compared with institutional settings (Emerson 2001 as cited in Gated, 2003, pg. 88).

2.3 Group Home

There are various kinds of group housing solutions, with a greater or lesser dependence on staff support (Gates, 2003, pg. 533). For example, in Sweden most of the people now have moved to group homes, each with their own contract of their own flat, consisting of a kitchen, bedroom, bathroom and living room. Four or five person can live in the same house sharing some communal areas such as rooms for laundry, a large living room and a staff room. Staffing is provided on different levels in order to enable each person to live as independently as possible (Gates, 2003, pg. 533). Usually no more than six people live in a house, and a single organisation controls the house and provides support services. Group homes appear to remain the dominant accommodation model for people with intellectual disability moving out of institutional settings (Bostock et al. 2001 as cited in Gibson et al. 2001), and are generally accepted as an important community-based accommodation option. However, questions have been raised about the degree of autonomy and choice experienced by the residents of some group homes (AIHW: Maples & Madden 1996; Parmenter et al. 1994 as cited in Gibson et al. 2001). Increasingly, the group home is being seen as a half-way house, in both the physical and policy senses, in the evolving deinstitutionalisation process. Usually, houses with approximately 12-30 people, were often referred to as 'half-way houses' and were usually run by social service departments. The 'half-way' referred to them being half way between a hospital and independent community living (Gates, 2003, pg. 86). Heron, 1982 (Gates, 2003, pg.86) states that, despite being much smaller than institutions, many of these establishments

were still very institutionalised, and sometimes continued to perpetuate systems that provided block treatment and depersonalized form of care.

2.4 Learning Disability/Intellectual disability/Mental Retardation/Developmental disability

In Europe the term Learning disability is used to refer to people with Intellectual disability or Mental retardation which is used in USA. Learning Disability is relatively a new term, the origin of the term lies in a speech to Mencap by Stephen Dorrell, Minister for Health in England in 1991 (Gates, 2003). There are a number of different terms used within Europe, the most common being mental or intellectual handicap, mental retardation, learning disabilities and intellectual disabilities (Beadle-Brown et al. 2003).

The project 'Included in society' defines Intellectual disability (Mental retardation)/learning disability as a condition where people have significant difficulties in learning and understanding due to an incomplete development of intelligence. Their skills in areas such as cognition, language, motor and social abilities can be permanently impaired. Most needs of people with intellectual disabilities are the same as other people: social contact, security, adequate housing, education, work, etc. Some might need additional education, but can live independently with some support. Others need life-long educational and social support. All people with intellectual disabilities are able to express their needs and wishes; they do not, however, always express themselves in a verbal form.

In the USA the term 'mental retardation' is widely used in the classification of 'learning Disability'. The USA system is based on ICD-10 classification of mental and behaviour disorders (WHO 1993 as cited in Gates, 2003). In USA the American Association on Mental Retardation defines learning disability as follows:

'Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18' (AAMR, 2002).

In UK the term learning disability is used, and this is accepted to mean:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence),with,
- A reduced ability to cope independently (impaired social functioning);
- Which started before adulthood, with a lasting effect on development. (DOH 2001, as cited in Gates, 2003).

The Czech Republic adopted the World Health Organization (WHO) classification of intellectual disability in 1992. According to this classification, intellectual disability is linked to IQ, and ranges across four main levels: mild; moderate; severe; and profound (World Health Organization, 1992 as cited in Barbara & Siska, 2006).

In this research paper the terms learning disability, intellectual disability, developmental disability and mental retardation will be used interchangeably.

2.5 History of Institutionalisation

Institutions for disabled people were built with good intentions: the idea was that people with special needs would have those needs met more effectively if they were all gathered in the same place. However, altruism was not always the only motivation: through institutionalisation, society no longer needed to concern itself with disabled people. In many cases, disabled people were segregated from society so effectively that their very existence was completely forgotten by many non-disabled people in the 'outside world' (Included in society)

The 19th century charity and medical model in the developed countries looked at disabled people as medical problems, who if not curable, need to be 'helped' or 'subjected' to particular regimes of 'moral management', discipline and segregation. This brought about the construction of institutions for people with disabilities. In these institutions all aspects of life were conducted in the same place, in the company of large number of people, all people were required to do the same thing together, and all parts of the day's activities were routinely

and tightly scheduled and controlled by officials in the same place. The consequence for the inmate was institutionalization and a resultant loss of sense of self. Goffman (1961) as cited in Hughes (1998) refers to this as "institutional dehumanization".

The first institutions or asylums accommodated people with both learning disabilities and mental illness, and they were introduced in the early part of 19th century. The over riding belief at this point was that people with learning disabilities could, with appropriate education and training, return to live in their own communities and have a contributory role to play. However, with the increasing fear that people with learning disabilities were among a number of social groups contributing to the degeneration of society, asylums in the first part of 20th century became more custodial and less reforming in nature (Gates, 2003, pg. 50). Institutional care carried with it a number of distinct characteristics, which Goffman (1961 as cited in Huges,1998) has summarized through his work, 'asylum'. This included block treatment, rigidity of the system, depersonalization and social distance between staff and residents (Gates, 2003, pg. 53).

The classic and often quoted definition is that provided by Goffman in 1961:

"A basic social arrangement in modern society is that the individual tends to sleep, play and work in different places, with different co-participants, under different authorities, and without an overall rational plan. The central feature of total institutions can be described as a breakdown of the barriers ordinarily separating these three spheres of life. First, all aspects of life are conducted in the same place and under the same single authority. Second, each phase of the member's daily activity is carried on in the immediate company of a large batch of others, all of whom are treated alike and required to do the same thing together. Third, all phases of the day's activities are tightly scheduled, with one activity leading at a prearranged time into the next, the whole sequence of activities being imposed from above by a system of explicit formal rulings and a body of officials. Finally, the various enforced activities are brought together into a single rational plan purportedly designed to fulfill the official aims of the institution". (Goffman 1968/1961:17 as cited in Huges, 1998)

Institutions symbolize regimentation, isolation from the community, lack of independence, dignity and privacy, poor quality of care, and control by others. Deinstitutionalisation movement for the first time got translated from philosophy into tangible social program in the United States (Dear & Wolch, 1987 as cited in Gibson et al. 2001)

There also have been numerous reports about large residential institutions which detail unacceptable conditions and intolerable violations of the human rights and dignity of residents. In spite of this, very little has been done to alter the policy of segregating disabled people from society, which in itself constitutes a major human rights violation (Included in Society). The actual confinement in an institution perpetrates unwarranted assumptions that the individual is incapable of participating in community life (Olmstead, 1999 as cited in Included in Society)

ECCL uses the following definition of the term "institution":

"An institution is any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size." (European Coalition for community Living)

2.6 Deinstitutionalisation and Normalisation

The terms Deinstitutionalisation and Normalisation go hand in hand and cannot be separate. The term deinstitutionalisation has traditionally been most closely associated with mental health and intellectual disability. Although it's original meaning lay in relation to the movement of actual individuals from an institutional setting to a community setting, over the time the term has attained a broader meaning in policy debates (Beadle-Brown et al. 2003). Deinstitutionalisation is a shift in the system of service delivery. And the process can be observed in a diverse array of service areas, including aged care, out-of-home care for children, services for people with disabilities, accommodation for homeless and acute hospital service (Beadle-Brown et al. 2003)

In Australia Deinstitutionalisation brought about the philosophy of care which emphasised better outcomes for individuals, and maximize their independence. In more recent times, deinstitutionalisation has emerged as a vehicle for promoting choice and independence. It was about the need to create community based alternatives as much as the need to close large-scale institutions, and it was also about the need to reform institutional care itself (Gibson et al. 2001). Parmenter (1994) as cited in Beadle-Brown et al. 2003, for example, has pointed to the prime importance of trying to determine the quality of life of people with a disability, wherever they live, and Young et al. (1998) as cited in Beadle-Brown et al. 2003 have identified with some concern the relative lack of critical evaluation of deinstitutionalisation initiatives in Australia.

The concept of normalisation, first introduced in Denmark in 1959 as part of Mental Retardation act, was initially used to define the creation of 'an existence for the mentally retarded as close to normal living conditions as possible'(Bank-Mikkelson, 1980 as cited in Gates,2003, pg. 54). The initial definition however tended to focus on securing normal housing, education and work and leisure conditions for people with learning disabilities. It was later adapted in Sweden to encapsulate patterns and conditions of living that equated to those of ordinary citizens and was redefined as 'making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of society' (Nirje, 1980 as cited in Gates, 2003, pg. 54). These included the rhythm of the day, the week, the month or year, the development of heterosexual relationships, economic and environmental standards and self determination. It is the case that these initial definitions of normalisation have been criticised on the grounds that, although promoting equal rights for people with learning disabilities, they did not support the notion of integration (Emerson, 1992 as cited in Gates, 2003, pg. 54). Their aims and objectives could be achieved without people with learning disabilities having to participate in any meaningful way within mainstream society. These limitations were recognize by Wolfensberger (1972), and normalisation was hence redefined as the 'utilisation of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible' (Wolfensberger, 1972 as cited in Gates, 2003, pg. 54).

However, the definition was to undergo a further modification in an attempt to emphasise the need for people with learning disabilities to fulfill socially valued roles, which Wolfensberger deemed to be the highest goal that could be achieved through normalisation. The term normalisation was hence replaced by the term 'social role valorisation' and that referred to the creation, support and defence of valued social roles for people at risk of devaluation (Wolfensberger, 1998 as cited in Gates, 2003, pg.55). This concept of normalisation or social role valorization was underpinned by seven main service principles from which O'Brien & Tyne(1981) as cited in Gates, 2003(pg. 55), identified five service accomplishments. They are community presence, choice, competence, respect and community participation. Since then services to people with learning disabilities were based on these definitive framework for Organisations then and Organisations now to strive for.

In this study out of the 5 services mentioned above by O'Brien & Tyne(1981) as cited in Gates, 2003(pg. 55) one of the services namely the 'choice' is evaluated in these group homes with people with intellectual disabilities using the choice questionnaire(Stancliffe & Parmenter, 1999).

A key concept associated with Principle of Normalisation was that of the least restrictive alternative principle, which requires that the level of support provided should be at the minimum level to support the person with a disability. The intention of this principle is not to minimize assistance, but rather to minimize the creation of dependence (or indeed to avoid interference with the further development of individual's independence). There are many different definitions of what Normalisation means , but Nirje (1980 as cited in Crichton, 1998) summarizes normalisation as ' making available to mentally retarded people patterns of life and conditions of everyday living which are *as close as* possible to the regular circumstances and ways of life of society'. Normalisation does not assume that someone with intellectual disability has normal abilities, but it does advocate the maximization of individual's abilities and choices. This could only be achieved if the quality of life of people with intellectual disabilities improves in whichever setting they live in.

2.7 Quality of Life (QoL)

The World Health Organisation (WHO), States that:

"QoL is defined as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment" (WHO, in Bowling, 1995 as cited in Felton, 2003).

Cummins (1997) as cited in Felton, 2003, a leading QoL researcher and developer of ComQol, provides the following widely accepted statement:

"Quality of life is both objective and subjective, each axis being the aggregate of seven domains: material well-being, health, productivity, intimacy, safety, community and emotional well- being. Objective domains comprise culturally relevant measures of objective well- being. Subjective domains comprise domain satisfaction weighted by their importance to individual."

QoL is a multidimensional concept which is influential by issues of cultural and personal relativity (Felton, 2003).

QoL measurement currently represents the most conceptually sophisticated form of quantitative measurement available and part of the recent interest in this method is due to the realization that complex interventions require equally sophisticated measures (Baker and Intagliata, 1982 as cited in Felton, 2003). Felton, 2003 states that the concept of QOL offers social workers/researchers the potential 'to assess outcomes through a patient centered approach' which '.... fits superbly with social work's professional values and ethics in "starting where the client is" '(Berkman and Maramaldi, 2001 as cited in Felton, 2003).

Quality of life (QoL) became a central issue in the field of rehabilitation in the 1990s (Schalock *et al.* 1989; Goode 1990 as cited in Schwartz & Rabinovitz, 2003). Health and human services have embraced the concept of QoL both as a sensitizing notion and as an overarching principle of service delivery (Schalock *et al. 2000* as cited in Schwartz & Rabinovitz, 2003). Quality of life has a multi-element structure consisting of different domains. In the international quality of life literature, a number of domains or dimensions of well-being have been identified, including: (i) social relationships and interaction, (ii) psychological well-being and personal satisfaction, (iii) employment, (iv) self-determination, autonomy and personal choice, (v) recreation and leisure, (vi) personal competence, community adjustment and independent living skills; (vii) residential environment, (viii) community integration, (ix) normalization, support services received, (x) individual and demographic indicators, (xi) personal development and fulfillment, (xii) social acceptance, social status and ecological fit, (xiii) physical and material well-being and (xiv) civic responsibility (Hughes et al. 1995 as cited in Petry, Maes and Vlaskamp, 2005). Schalock et al. (2002) as cited in Petry, Maes and Vlaskamp, 2005 mentioned eight core domains of quality of life in their consensus document on quality of life: (i) emotional well-being, (ii) interpersonal relations, (iii) material well-being, (iv) personal development, (v) physical well-being, (vi) self-determination, (vii) social inclusion and (viii) rights. Felce and Perry (1995) as cited in Maes, Geeraert &Bruel (2000) defined quality of life as 'an overall general well-being that comprises objective descriptors and subjective evaluations of physical, material, social, and emotional well-being together with the extent of personal development and purposeful activity, all weighted by a personal set of values. People with developmental and intellectual disabilities have an improved quality of life when they have some control over resources intended to provide supports (Conroy, 2004). One important factor that affects quality of life is the amount of decision making opportunity a person has in his life. Level of choice an individual with intellectual disability can exert in his day-to-day life during his stay in a group home, can predict the quality of life he/she has in the group home.

2.8 Importance of choice making

Personal freedom and control over one's life are cherished rights within our society (Stancliff and Parmenter, 1999). Lifestyle measures are seen as being much more comprehensive and

reflect most closely normalization values (Bellamy, Newton, LeBaron, Harper, 1990). To make it possible to achieve the vision of disabled people living as equal citizens included in society, various goals need to be established (Included in society). In particular, the replacement of traditional forms of institutional residential provision with small community-based residential supports was frequently advocated on the basis that such services are likely to facilitate choice and self-determination among people with ID (Heal *et al.* 1988; Taylor *et al.* 1988; Meyer *et al.* 1991; Mansell & Ericsson 1996 as cited in Hatton, Emerson, Robertson, Gregory, Kessissoglou & Walsh, 2004). High-quality care is no longer a favour; clients have the fundamental right to demand quality care (Maes, Geeraert &Bruel 2000). Notions of choice and self-determination have been at the centre of the ideologies and policies that have shaped services for people with intellectual disability (ID) in the UK, North America and Australasia over the past three decades (Hatton, Emerson, Robertson, Gregory, Kessissoglou &Walsh, 2004). Available research suggests that adults with intellectual disability make fewer choices than do peers without disability (Kishi, Teelucksingh, Zollers, Park-Lee, and Meyer, 1998; Parsons, McCarn, and Reid, 1993; Wehmeyer and Metzler, 1995 as cited in Stancliff and Parmenter, 1999). Choice is a highly valued outcome, but it is less available to many people with intellectual disability, and features of some service settings may restrict choice even further (Stancliffe &Parmenter, 1999).

In UK the principles of normalisation were adapted by O'Brien & Tyne (1981) as cited in Gates, 2003(pg. 55) and they identified 5 service accomplishments, namely, community presence, choice, competence, respect and community participation to operationalise the concept. Out of these five service accomplishments, in my study I have tried to evaluate the availability of choice for people with intellectual disability when living in a group home. Under choice it should be ensured that the service users are supported in making choices about their lives by encouraging people to understand their situation, the option they face and helping them to act in their own interest both in small everyday matters and in such important issues as who to live with and what type of work to do (O'Brien & Tyne (1981) cited by Emerson (1992) as cited in Gates, 2003, pg. 55).

In recent years, the self-determination construct has received increased visibility and utilization in the field of intellectual disability (ID). There is general acknowledgement within the educational (Wehmeyer *et al.1998*; Field *et al.1998*· Wehmeyer 1999 as cited in Wehmeyer and Bolding, 2001) and adult services (Nerney & Shumway1996; ASD 1999; Wehmeyer 2001 as cited in Wehmeyer and Bolding, 2001) literature that 'self-determination' is important for children, adolescents and adults with ID (Wehmeyer and Bolding, 2001). A person with intellectual disability should have control over his/her life, and make his/her own choices and decisions (Bach & Rioux, 1996; Wehmeyer 1994 as cited in Maes, Geeraert &Bruel 2000). Self-determination is exercised when a person articulates aspirations, and makes plans and decisions to achieve these. Bearing in mind personal competencies, opportunities and support to achieve autonomy and responsibility are gradually offered (Maes, Geeraert &Bruel 2000).

Choice is widely regarded as an essential component of quality of life (Stancliffe &Parmenter, 1999). O'Brien (1987) as cited in Stancliff and Parmenter (1999) listed choice as one of the five accomplishments essential to quality of life, and other conceptualizations of this construct also feature choice-making as an essential component (Hughes, Hawang, Kim, Eisenman & Killian, 1995 as cited in Stancliff and Parmenter, 1999). Although people with ID living in smaller community-based residential settings generally experience greater choice than residents in larger, more institutional settings (Stancliffe & Abery 1997 ; Stancliffe *et al.* 2000 ; Robertson *et al.* 2001 as cited in Hatton, Emerson, Robertson, Gregory, Kessissoglou &walsh, 2004), such choice is not an inevitable concomitant of deinstitutionalization and rarely extends to major life choices, such as where and with whom to live or the hiring and firing of staff (Emerson & Hatton 1996 ; Stalker & Harris 1998 ; Robertson *et al.* 2001 as cited in Hatton, Emerson, Robertson, Gregory, Kessissoglou & Walsh, 2004). A number of factors have been found to be associated with greater choice: smaller size of home (Tossebro 1995 ; Stancliffe 1997); being supported in independent or supported living schemes (Wehmeyer & Bolding 1999; Stancliffe *et al.* 2000; Robertson *et al.* 2001); and living in a less intensively staffed environment (Stancliffe 1997 as cited in Hatton, Emerson, Robertson, Gregory, Kessissoglou & Walsh, 2004).

People should have the right to make choices about their lives, such as where they live, with whom they associate, with whom they wish to develop friendships and other relationships, and the type of services they use. If individuals have difficulties making decisions, they should be given as much support and assistance as possible to make choices for themselves and express their preferences (Included in Society).

Stancliffe & Parmenter, 1999 has cited that attempts have been made to quantify choice availability by researchers from Australia (Jenkinson, Copeland, Drivas, Scoon, & Yap, 1992; Kent, 1990; Parmenter, Briggs, & Sullivan, 1991), the United States (Colorado Division for Developmental Disabilities, 1992; Harner &Heal, 1993; Kishi et al., 1998; Schalock & Keith, 1993; Selter & Selter, 1978; Wehmeyer & Metzler, 1995) and elsewhere (Schwartz, 1995; Tossebro, 1995. As is common in a newly developing area of research, most of the scales used to assess choice availability in these studies had unknown psychometric characteristics. Where more rigorous evaluation of these scales was attempted, the findings have frequently revealed unsatisfactory reliability or validity(Stancliffe &Parmenter, 1999). Stancliffe &Parmenter, 1999 developed an Australian scale- a reliable and valid self-report and third-party-report instrument to assess the degree of personal control, or choice, exercised by people with intellectual disability over a variety of aspects of their lives. I have used the same questionnaire to assess the degree of choice/personal control in 2 group homes, one run by service providers who were social workers and another run by parents.

When we address quality of life and choice making with respect to people with intellectual disabilities, we cannot not touch upon what independence and empowerment for people with intellectual disabilities mean, when the issue of community living need to be addressed.

2.9 "Independence" in relation to disability

As Brisenden (1986, as cited in Hughes, 1998) notes, 'Independence is not linked to the physical or intellectual capacity to care for oneself without assistance; independence is created by having assistance when and how one requires it, by being able to choose when and how care takes place.' According to this alternative construction, independence or personal

autonomy is about controlling one's own life, and that personal independence may in turn be facilitated through another body(Campbell and Oliver in 1996 as cited in Hughes 1998)

Oliver (1990 as cited in Carnaby 1998) suggests that an unsatisfactory position is compounded by the term's political connotations:

….. independence suggests that the individual needs no assistance whatever from anyone else and this fits nicely with the current political rhetoric which stresses competitive individualism. In reality, of course, no one in a modern industrial society is completely independent: we live in a state of mutual interdependence. The dependence of disabled people therefore, is not a feature which marks them out as different in kind from the rest of the population but different in degree.(p.84)

The important word here is mutual. Before labeling the person with intellectual disabilities or any disability as dependent and fearing them, and striving towards independence, Oliver, 1990 as cited in Carnaby 1998 pause to recognize that even the most so-called independent people without any disabilities have areas of their lives in which they have needs and dependencies. As human beings we all live within our limitations, trying to work around our weaknesses' and using our strengths. If we do this, then why not accept the person with disability as they are, by focusing on their abilities and not their inabilities and work towards creating a more inclusive society.

Miles-Paul emphasized that the closure of institutions needs to be accompanied by the development of alternatives for community living. He also added that it is important to avoid the so-called "independence trap", according to which people with disabilities must prove that they can do everything by themselves, with no support, if they want to live independently or find employment (Working Together for Community Living- Report from the Right to live in the Community Seminar).

2.10 "Empowerment/ self-determination" in relation to disability

Is it about performing all day to day activities by oneself without seeking any help? Is it about doing things that is considered as normal by the majority of the people in this society, because of the reason that all the other so called 'normal people' perform it? Is it about showing how strong a person is physically? I believe empowerment is all about taking responsibilities in life. It is about making our own choices and decisions in every single step in our life and taking ownership. If we cannot do that by ourselves, then it is the responsibility of the community to take us through the process of decision making. That is what community living is all about. Historically, the term self-determination has referred to the right of nations to self- governance. The term was appropriated by disability rights advocates and people with disabilities to refer to their "right" to have control in their lives (e.g., Nirje, 1972; Williams, 1989 as cited in Wehmeyer& Schwartz (1998). In this context, self-determination and empowerment are often used interchangeably. Empowerment is a term usually associated with a social movement and typically is used, as Rappaport (1981) as cited in Wehmeyer & Schwartz (1998) stated, in reference to actions that "enhance the possibilities for people to control their lives" (p. 15). Because self-determination has been linked to positive adult outcomes and enhanced quality of life, it is important to consider ways to enable people with intellectual disability to live and work in their community.

As this study is carried in Czech Republic, an over all picture regarding the deinstitutionalisation and normalisation movement all over Europe would give this study a broader perspective and would help us compare the progress in Czech Republic with respect to the same after the fall of the communist rule in 1989.

2.11 European context

Over the past ten years, reports have highlighted serious human rights abuses within institutions in Eastern and Central Europe (Mental Disability Rights International, 1997; Mental Disability Advocacy Centre, 2003 as cited in Included in Society). By maintaining children with disabilities in separate, segregated facilities, Soviet society was able to exist as if there were no people with disabilities. People with disabilities were invisible (MDRI, 1999

ascited in Barbara & Siska, 2006). These ideas prevailed throughout much of Central and Eastern Europe during most of the 20th century (Barbara & Siska, 2006).

Government policy in Europe in the past has often been to place disabled people in large residential institutions (Included in society). In some countries in Europe discrimination against people with intellectual disabilities is unlawful. However, in most countries there is scope for having people with intellectual disabilities declared legally incompetent and therefore either removing any decision-making authority from them or providing third-party supervision or substitutes for decision-making (Beadle-Brown et al. 2003). Self help and advocacy organizations of disabled people are voicing a widely-held opinion that these settings are no longer acceptable in modern European societies (Included in society).

A part of having civil rights is being able to participate in the life of the home and community, access the same activities, facilities and services as other people. However, in all countries people with severe and profound intellectual disabilities are unable to exercise these rights to the full extent possible because services fail to provide enough skilled support in the community or are based on congregate care in large and for the most parts isolated institutionalised services (Beadle-Brown et al. 2003).

The project Included in Society when trying to find out choice making and autonomy of the residents in institutions in Europe, found out that, more choice is afforded to those residents with the lowest support needs. With regard to residents taking part in everyday activities, in all countries studied, the level of opportunity for participation in daily activities was rather low.

2.11.1 The EU disability action plan

The multi annual action program that the European Union established following the European Year of People with Disabilities 2003, provides important possibilities for promoting community-based service provision. In this respect, it is proposed that the Commission should support the existing partnership of the "Included in Society" project to establish the "European Coalition for Community Living". The coalition will constantly monitor and

report on the requirements for residential services for disabled persons and the development of community based care in Europe (Included in society). In general, people are now afforded rights rather than offered charity but this tends to be different from actually getting those rights and accessing the services – intentions are good but practice is different from what is available on paper in many states. Instead of allocating services on the basis of 'intellectual disability', services would be allocated on the basis of 'housing need' or 'assistance needs' or 'financial needs' and these services would be the same whatever the presumed cause of the need (Beadle-Brown et al. 2003). All member states of the European Union have committed themselves to the protection and promotion of human rights. Its new social policies seek to ensure that disability issues are addressed in all areas of life. In addition, it is EU policy to avoid exclusion and to encourage the social integration of disabled people. There have been numerous reports about large residential institutions in European Union member states, which have revealed details of unacceptable conditions and intolerable violations of human rights and dignity (Included in society).

The Czech Republic, which has lately joined the EU has committed to work in accordance with EU disability action plan. As a result of this, 'Act 108/2006 sb' is going to be implemented from the coming year 2007.

2.12 Intellectual Disability and Czech Republic

Following the establishment of communist Party rule in Czechoslovakia after the Second World War, all social care services were taken over by the state, including services provided by the non-government organisations (NGOs), community and private institutions (Potucek, 1993 as cited in Scragg, 1999). Independent organisations providing services for people with learning disabilities were regarded as a threat to communist rule, because they represented a partial source of opposition to state control (Lackoz, 1994 as cited in Scragg, 1999). Communist policy in the Czech Republic rendered individuals with intellectual disability virtually invisible. These individuals were segregated from mainstream society through placement into residential institutions usually located in old buildings in remote regions (Barbara and Siska, 2006). This period, with centralized bureaucracy which took little account of individual need, emphasised the number of facilities and people served, but

showed less concern for the quality or appropriateness of services provided. The collapse of communism in 1989 brought about a series of fundamental changes in Czech society, including the restoration of parliamentary democracy and constitutional guarantees of human and civil rights (Pravlik, 1996 as cited in Scragg, 1999). According to one author, 'The model of institutionalized care for people with disabilities or chronic illness has not changed significantly ... since the fall of communism in 1989' (Holland, 2003 as cited in Barbara & Siska, 2006). A void remains with regard to community-based services (Barbara & Siska, 2006).

'Included in Society', report that in the Czech Republic, a lot of services still work with medical personnel. There is a medical approach towards disability and the care for people with disabilities. There is a lot of resistance from medical staff when they feel that their position is endangered because of the change in perspective inherent in a move towards more inclusive methodologies. Information, from the Czech Republic, has shown that the long waiting lists are misinterpreted as there being a big interest in the type of services for people with disabilities currently offered and this is used as an argument for the extension of the capacity of these large residential settings. This also has the effect of preventing the development, by the state, of alternative services like day opportunities or other less intensive forms of support like sheltered housing (Included in Society).

In Czech Republic the process of de-institutionalisation has not been fully started. The State legally guarantees and finances on a regular basis only two kinds of services: community/home care for the elderly and institutional care run by regional governments or municipalities. This system puts NGOs, which provide community based social services, into an unequal position. Therefore, care in institutions largely exceeds community based services. Inclusion, empowerment of adults with intellectual disabilities and their further opportunities remain limited [Inclusion Europe (The European association of societies of person with intellectual disability and their families) and SPMP (Association for help to mentally handicapped in the Czech Republic), People with Intellectual disability and their families in Czech Republic]. A significant shift in social care provision occurred with de-monopolization of the state role in provision of social care in 1990, which led to a pluralism

of social services for persons with intellectual disability. At the same time, there was rapid growth in NGOs, new services founded by professionals appeared, and a certain decentralization of services from the State to local authorities occurred. These new services attempted to fill in gaps in service provision by providing day services, small-scale residential accommodation, vocational training programs and so on (Barbara and Siska, 2006). As there is no directory of NGOs providing services to individuals with ID in the Czech Republic, at this time it is not possible to determine the actual number or extent of community-based services (Barbara & Siska, 2006).

But still extraordinary changes have taken place in social care services in the Czech Republic since the 1989 'Velvet Revolution'. This is evidenced in the shift from a dominant ideology of 'socialist utopia', where people with intellectual disability were hidden, to resurgence of a new democracy with opportunities for persons with intellectual disability to live alongside others in the community. This has been made possible by rejection of discredited ideologies and growth of alternative service forms provided by NGOs (Barbara and Siska, 2006). The financing system for institutions is a legacy from the 40 years when the state was the only provider of social services. Funding goes directly to providers, not to clients or their families, so clients have little choice in services or service providers. State contributions depend on the number of occupied beds: the amount per bed has not changed since 1995 (Barbara and Siska, 2006).

2.12.1 Czech Republic Legislation

A Government Board for Persons with Disability was established in 1991, which introduced a National Plan of Actions for Persons with Disability in 1992. By 1993, the Czech Republic was recognized as being among the countries with the most advanced national concept of support for citizens with disability. National Plans continue to be introduced, and although not legally binding (they are government resolutions), they do set broad goals (Barbara & Siska, 2006).

After 13 years in Czech Republic "Act 108/2006 sb"" has been passed, which is expected to be implemented from January 2007. Main features of this act being:

- Benefits of social services from the ministry will go directly to the users. Depending on the degree of disability, the funds will be distributed.
- Regions are responsible for planning the social services. Municipalities will work close to the community and families, where by people with disabilities can approach them for any kind of services.
- Inspection of social services is controlled at the level of Ministry and Regions. Through this standard of quality of services rendered, duties of service providers and social workers and lastly the registration of service providers are monitored.
- Promotion of self-advocacy.

The Act over all try to provide equal opportunities to all providers and renders no differences to social services run by region or municipality or individual keeping in mind "All people are the citizens of equal rights"(Dr. Marketa Holeckova, Ministry of social services, interviewed on 3rd July 2006, see appendices).

CHAPTER 3

3. RESEARCH METHODOLOGY

3.1 Introduction

Schumacher and McMillan define research as that which `systematically describes or measures reality' (1993, p3). Research is the one that is carried out close to oneself, while trying to validate ones own ideas and queries about his/her own practice or the present practices. Researchers, in other words, must view the research as a sense-making and co-production process between themselves and the people they are researching. Petra Ponte (2005) says that, researches must also see critical self-reflection on their own meaning constructions as part of the research process. It is a process in which the data is used to inform the practice of the researcher as well. According to von Glasersfeld as cited in Vanderstraeten and Biesta, 'authentic' learning depends on seeing a problem as 'one's own problem', as an obstacle that obstructs one's progress toward a goal. Researchers and scholars employ various research paradigms to guide them through the course of knowledge seeking. Within the research process the beliefs a researcher holds will reflect in the way research is designed, how data is both collected and analyzed and how research results are presented. For the researcher it is important to recognize their paradigm, as it allows identifying their role in the research process, determining the course of any research project and distinguishing other perspectives (Williams 1998).

Paradigms in human and social sciences help us understand phenomena. They encompass both theories and methods. A paradigm is a conceptual framework for making sense out of what we do. Thomas Kuhn, in the Structure of Scientific Revolutions (1962) refers to paradigm as a constellation of concepts, values, perceptions and practices shared by a community which forms a particular vision of reality that is the basis of the way a community organizes itself." According to Burrell and Morgan (1979; 24) as cited in Williams 1998, "To be located in a particular paradigm is to view the world in a particular way." And indeed paradigm has been termed a (Patton, 1990; 37 as cited in Williams 1998) "world view".

In this research, I have combined both quantitative and qualitative paradigms to generate data for comparative study of two group homes namely Group home A , where social workers and specialists in the field of disability are the service providers and Group home B, where parents are the service providers. In particular the quantitative study is on finding how much of choice is exercised by people with intellectual disabilities living in these group homes in a day-to-day basis using Stancliff and Parmenter's (1999) 'the choice questionnaire'. For the qualitative study the data is generated via an unstructured interview with the head of the group home using an interpreter (Group home B) and with one of the staff from the home (Group home A) who could speak English. Through this informal interview a number of key issues were raised in conversational style (Cohen et al. 2005) and information concerned with the history, philosophy, the daily routine, the features of the group home and the involvement of the residents in the running of the group home were gathered. Unstructured observation was done whenever I went to the group home for getting the choice questionnaires answered, to find out how the group home is set and organised and how the relationship between the residents and the staff are.

3.2 Qualitative study

Qualitative studies typically include an emic (insider to phenomenon) in contrast to quantitative studies' etic (outsider) perspective (Brantlinger et al. 2005). Qualitative studies in the field of special education remind the readers to think what they think they really know and who they think they are as professionals and open space for discussion with recipients of special education services about the characteristics of the good life in a pluralistic, democratic society (Harry et al., 2002; Pugach, 2001 as cited in Brantlinger et al. 2005)

Apart from capturing the perspectives of people with disabilities and their friends and family members qualitative studies can produce scientifically sound evidence that informs policy and practice." Qualitative research is not done for purposes of generalization but rather to produce evidence based on the exploration of specific contexts and particular individuals." Though qualitative research cannot create universal and essential knowledge for policy or offer universal prescriptions for practice, they can show how their results can inform policymakers and practitioners (Brantlinger et al. 2005)

The qualitative paradigm is termed the constructivist approach or naturalistic, the interpretive approach, or the post positivist or postmodern perspective as a counter movement to the positivist tradition or the quantitative paradigm in the late 19th century (Creswell 1994). Qualitative research's theoretical orientations span the spectrum from positivist/post positivist to constructivist frame works; it includes the critical perspective, sometimes referred to as ideological/orientational framework (Patton 1990 cited in Pugach) that focuses on inequalities and power differentials and transforming society to reduce or eradicate those inequities. Many of these qualitative methods (ethnographic, participant observation, case study, phenomological, constructionist, and interpretive) developed out of people who had little or no voice in society (Lackaff et al. 1997). By focusing on participants' personal meanings, qualitative research "gives voice" to people who have been historically silenced or marginalized (Brantlinger et al. 2005). In this research the residents of the group home, people with intellectual disabilities are directly involved in the study. In qualitative research, data analysis is inductive rather than a priori and deductive, the research design emerges over time, and the outcomes of the research are negotiable. Further the research is holistic, that is, it seeks a description and interpretation of 'total phenomena' (Cohen et al. 2005, pg. 138).

3.3 Quantitative study

However, logical positivism, or quantitative research, uses experimental methods and quantitative measures to test hypothetical generalizations (Hoepfl 1997). A quantitative study is intended to develop generalizations that contribute to the theory and thereby enable to predict, explain and understand some phenomenon (Creswell 1994). The use of standardized quantitative methods continue to offer some advantages in effectiveness research through enhancing the generalisability of research findings (dependent on research design) and enable comparisons between individuals and populations (Corcoran and Fischer, 2000; Berkman and Maramaldi, 2001 as cited in Felton, 2003). In this study Stancliff and Parmenter's (1999) 'the choice questionnaire' is used to get data from people with intellectual disabilities to evaluate the amount of choice they have in making decisions for themselves or with help while living in the group home. The questionnaire does not measure the ability of the person with intellectual disabilities living in the group home but the choice exercised by them in the group home with respect to issues related to daily living.

3.3.1 Quality of Life Measurement

Over the last couple of decades, a meaning-based approach to quality of life (QoL) has emerged as an important vehicle for the assessment of client outcomes in research and programme-evaluation contexts as the clients are looked unto as a self-reflecting and experiencing individuals (Felton, 2005). Although researchers prefer qualitative methods as a means of incorporating the subjective meaning of the client into measurement (Scott, 2002 as cited in Felton, 2003), use of standardized quantitative methods continue to offer some advantages in effectiveness research through enhancing the generalisability of research findings (dependent on research design) and enable comparisons between individuals and populations (Corcoran and Fischer, 2000; Berkman and Maramaldi, 2001 as cited in Felton, 2003). In this study it is between two group homes. QoL measurement is seen by many to offer a more client-centered and meaningful method of quantitative measurement (Schipper et al., 1996; Berkman and Maramaldi, 2001 as cited in Felton, 2003)

Attempts to develop ways to measure quality of life enjoyed by people with learning disabilities have proliferated over the last two decades. The appeal of these approaches seems to stem from their attempt to bring in some experiential or real life evidence to the study of quality (Gates, 2003, pg. 99). 'The quality of life of service users has been increasingly proposed as the ultimate criterion for the assessment of the effectiveness of social care delivery in the field of learning disabilities' (Perry and Felce 1995 as cited in Gates, 2003, pg. 99).

In Britain and other countries, the expansion of community provision has been paralleled by increased interest in the conceptualization and measurement of quality of life (QoL). The term 'quality of life' is generally considered to encompass the breadth of life experience (Perry and Felce, 2003). In keeping with this, most commentators agree that QoL should reflect various important domains of life (e.g. Campbell et al. 1976; Parmenter 1988; Schalock 1996a; Cummins 1997a; Felce 1997 as cited in Perry and Felcy, 2003). Felce (1997 as cited in Perry and Felcy, 2003) classified QoL into six life domains: physical well-being, material well-being, social well-being, productive wellbeing, emotional well-being and civic well-being.

One common approach to evaluate QoL among people with intellectual disability is to interview the person. If an individual is unable to be interviewed, it is common practice to ask a proxy to respond on the person's behalf. The assumption is that knowledgeable proxies can provide a satisfactory approximation of the responses the individual would give (Stancliffe, 1999). There have been findings of satisfactory proxy: consumer agreement (Schalock & Keith 1993; Rapley et al. 1998 as cited in Stancliffe, 1999) and of disagreement (Reiter & Bendov 1996; Rapley et al. 1998 as cited in Stancliffe, 1999). Hatton (1998) criticises that there are unresolveable methodological problems associated with measuring or assessing subjective indicators of quality of life, which mean that result of one person or one service cannot meaningfully be compared with results elsewhere. Moreover, he argues that the emphasis within quality of life measures on combining subjective with objective indicators tend to exclude those who cannot verbalise their preferences and feelings. In this study the opportunity to make choices experienced by the residents with intellectual disabilities living in the group home are scored using Stancliffe & Parmenter's "the choice questionnaire" to evaluate their Qol.

3.4Case study

This research work is a case study on group homes. In this case study 2 group homes for people with intellectual disabilities with different service providers are compared. In one group home (Group Home A) the social workers and specialists are the service providers and in the other group home (Group Home B) parents of people with intellectual disabilities are the service providers.

A case study is more relevant because it strive to portray 'what is it like' to be in a particular situation, to catch the close-up reality and 'think description' (Geertz, 1973 as cited in Cohen et al 2005, pg. 182) of participants' lived experiences of, thoughts about and feelings for, a situation. Hence it is important for events and situations to be allowed to speak for themselves rather than to be largely interpreted, evaluated or judged by the researcher (Cohen et al 2005, pg. 182). Case study is a preferred strategy when how or why questions are being posed, when the investigator has little control over events, and when the focus is on contemporary phenomenon with some real life context. Such explanatory case studies also

can be complemented by 2 other types- exploratory and descriptive case studies (Yin, 2003, pg.1). This study is a descriptive comparison of 2 group homes for people with intellectual disability run by 2 different service providers. Limitations that were encountered during this study were the time constrain because of which all stake holders could not be involved and the language barrier.

Comparative study of 2 group homes

Through this comparative study between 2 group homes an effort is made to find out whether there is any difference in how the group home is organised and is run when the initiatives are different. If there are differences, an attempt is made to understand why these differences exist. Other than the differences, even the similarities are figured out between these 2 group homes.

For the case study most part of the qualitative data is collected using an unstructured interview with the group home head or a staff and via unstructured observation. Because of the language barrier separate interviews could not be conducted with all the staff and other stake holders to gather qualitative information. The quantitative data is collected using the standardized choice questionnaire (Stancliffe &Parmenter, 1999). Three sets of data have been collected using the same questionnaire by slightly modifying the structure of the questions, based on to whom the questions were directed. This includes

- Residents scoring of the questionnaire
- Staff scoring of the questionnaire on behalf of the residents
- Staff scoring of the questionnaire under 2 different situations- in reality and in ideal.

To give a totally different dimension to this study, all the staffs were asked to answer the same questionnaire in 2 different situations. One regarding the present happening in the group home (reality) and the other one is about what they as a person and a staff would like to see happen in the group home with respect to the amount of choice that is available or that should be available for the residents. For this purpose the questionnaire was translated in Czech. Analysis is done by comparing the overall choice scores obtained through the questionnaire and also by conducting paired t-test (one tailed) between the scores obtained

from the residents and staff within a group home and t-test of difference of means for independent samples between the scores of the residents of the 2 group homes.

3.5 Methods

3.5.1 Interview

Unstructured interview was carried out with a staff from group home A and with the head of group home from group home B, both of whom volunteered to take part in the interview. Because of the language barrier an interpreter was used in group home B. The staff from group home A was able to give the interview in English. The interview was carried in a conversational style using "friendly" and "non-threatening" open-ended questions. Throughout the interview actual (conversational) questions were asked in an unbiased manner that served the needs of the line of inquiry. Interview was of open ended nature, in which the respondents were asked about the facts of a matter as well as their opinions about events. In some situations, the respondents were asked to propose his or her own insights into certain occurrences (Yin, 2003, pg. 90).

3.5.2 Observation

In a case study observational evidence is often useful in providing additional information about the topic being studied (Yin, 2003, pg.93). In this study unstructured direct observations were done in the group homes. For instance Morrison, 1993 as cited in Cohen et al. (2005 pg. 305) argues that observation enables the researcher to gather data on the physical setting (e.g. the physical environment and its organisation), the human setting (e.g. the organisation of the people, the characteristics and make up of the groups or individuals being observed, for instance gender, class), the interactional setting (e.g. the interactions that are taking place, formal, informal, planned, unplanned, verbal, non-verbal etc.) and the programme setting (e.g. the resources and their organisation, pedagogical styles, curricula and their style), which indicate about the climate and impoverishment of an organisation (Yin,2003, pg. 92). Unstructured observation refers to going into a situation and observing what is taking place before deciding on its significance for the research (Cohen et al. 2005). In this study, the

disposal of the clients and the staff within the group home and the setting and organisation of the group homes were observed.

3.5.3 The choice questionnaire

Although choice is widely regarded as an essential component of quality of life, researchers have made few attempts to develop and evaluate psychometrically sound instruments to measure the availability of choice to people with intellectual disability. The questionnaire that is been used apart from psychometric requirements of satisfactory reliability and validity, is planned in a way that the proposed scale be useable both as a self-report measure and by proxy informants. As far as possible, people with intellectual disability should receive opportunities to express their own views on outcomes in their lives, including choice (Heal &Siegelman, 1996 as cited in Stancliff and Parmenter, 1999) when we are talking about QoL and community living. In case where communication difficulties make this impracticable, it is also desirable that the scale can be completed by proxy, such as a carer. The study by Stancliff and Parmenter, 1999 focused on identifying scale items which are satisfactory for use for both self-report and proxy responses, which has been used in this study.

The choice questionnaire (Stancliffe 1995 as cited in Hatton et al. 2004; Stancliff and Parmenter, 1999) items relate to six domains: 'domestic activities, staff and the other people you live with'; 'money and spending'; 'health'; 'social activities, community access and personal relationships'; 'work/day activities'; and 'overall choice'. It can be completed by a carer, or the individual with intellectual disabilities. When interviewing people with intellectual disabilities, two additional items precede the main questionnaire items, one to test for recency bias in residents' responses, the other to assess acquiescence bias.

Characteristics of the questionnaire

Open-ended questions were mostly preferred because of there are fewer problems with response biases (Sigelman et al., 1983 as cited in Stancliff and Parmenter, 1999). Researchers who have used open-ended questions with people with intellectual disability have often found il helpful to ask questions in a number of ways and use follow-up questions to elicit the fullest response (Kabzems, 1985; Wyngaarden, 1981 as cited in Stancliff and Parmenter, 1999). As

may be seen in Appendix, many choice questionnaire items include several related questions and/or optional probes in parentheses. This approach of providing written probes was taken to aid in consistent presentation of items, although interviewers are free to probe further if needed. Because of the language barrier a staff, the residents knew well and who knew English as well carried out the test with the clients. I looked over the entire process and scored the questionnaire according to the responses of the residents.

Designing the scale as self-report instrument introduces a number of difficulties resulting from the well documented problems of response biases which can arise when interviewing people with intellectual disability (Heal &Sigelman, 1996; Rubin, 1995; Sigelman et al., 1983 as cited in Stancliff and Parmenter, 1999). Prominent among these biases are acquiescence, Nay-saying and recency. Acquiescence, or Yea-saying, is evident when the person replies "yes" to a yes/no question regardless of its content, even to the point of giving contradictory answers to oppositely worded questions about the same issue. Nay-saying involves replying negatively to yes/ no questions irrespective of content. Recency arises in relation to either/or and multiple choice questions when the last (most recently mentioned) alternative is selected regardless of its content. That is, these response biases are characterised by answers which result from the type of question asked rather than its content. The residents who took the questionnaire answered both these questions right.

3.6 Sampling

3.6.1 Non-probability sampling

The selectivity which is built into a non-probability sample derives from the researcher targeting a particular group, in the full knowledge that it does not represent the larger population; it simply represents itself. This is frequently the case in small scale research, like the one that is being carried out with two group homes, where no attempt to generalization is desired; this is frequently the case for some ethnographic research, action research or case study research (Cohen et. al 2005, pg. 102).

3.6.2 Purposive Sampling

In purposive sampling the researcher handpick the cases to be included in the sample on the basis of their judgement of their typicality. In this way, they build up a sample that is satisfactory to their specific needs (Cohen et. al 2005, pg. 103). In this study, the sample namely the people with intellectual disability living in group home has been specifically chosen to answer the choice questionnaire. I am aware of the fact that, whilst it may satisfy the researcher's needs to take this type of sample, it does not pretend to represent the wider population; it is deliberately and unashamedly selective and biased (Cohen et. al 2005, pg. 104). But a purposive sampling in a qualitative research enables the full scope of the issue to be explored (Cohen et. al 2005, pg. 138) which is the focus of this study.

3.7 Validity and reliability

In quantitative data validity might be improved through careful sampling, appropriate instrumentation and appropriate statistical treatments of data (Cohen et. al 2005, pg. 105). In this study I have used non-probability, purposive sampling, namely people with intellectual disabilities living in group homes run by service providers and parents. In qualitative study the focus of the study determines its boundaries, trustworthiness and its components replace more conventional views of reliability and validity (Cohen et al. 2005, pg. 138).

3.7.1 Validity

Maxwell, echoing Mishler (1990), as cited in Cohen et al. 2005 (pg. 106), suggested that 'understanding' is a more suitable term than 'validity' in qualitative research. We as researchers are part of the world that we are researching, and we cannot be completely objective about that, hence other people's perspectives are equally as valid as our own, and the task of the research is to uncover these. In qualitative data the subjectivity of respondents, their opinions, attitudes and perspectives together contribute to a degree of bias (Cohen et. al 2005). This is taken into consideration in this research. Validity, then, attaches to accounts, not to data or methods (Hammersley and Atkinson, 1983); it is the meaning that subjects give to data and inferences drawn from the data that are important (Cohen et al. 2005).

3.7.2Reliability

Reliability is essentially a synonym for consistency and replicability over time, over instruments and over groups of respondents. Use of a standardized questionnaire in this study makes this study reliable and replicable. During the interview a short summary of the information provided, immediately followed each question after the conversation, through which "member check" was done to make the data reliable.

3.8 Ethical Issues

Social scientists generally have the responsibility not only to their profession in its search for knowledge and quest for truth, but also for the subjects they depend on for their work. Whatever the specific nature of their work, social researchers should take into account the effects of the research on participants, and act in such a way as to preserve their dignity as human beings (Cohen et. al 2005).

3.8.1 Informed Consent

Social research necessitates obtaining the consent and co-operation of subjects who are to assist in investigations and of significant others in the institutions or organisations providing the research facilities (Cohen et. al 2005). I also believe that informed consent is absolutely essential in this study with persons with intellectual disabilities. During the data collection process, only those clients who were willing to answer the questionnaire were scored. For example in Group home A there were 11 clients with intellectual disabilities. Out of 11, only 8 of them took part in the research because one client was not willing to answer, another client was unwell and the third client had severe mental retardation. In Group home B out of 14 clients, only 6 volunteered to take part in the study. In both the group homes the choice and willingness of the clients were respected.

3.8.2 Anonymity and Confidentiality

Since this study focus on new innovative models of group home and their functioning in Czech Republic, I have tried to keep the sources anonymous. So no where in this research any kind of personal identification of the organisation in which this study was taken and the people interviewed would be mentioned. Responses of the residents and the staffs will not be

publicized and would only be used for this study. The people involved in this study were assured that they would remain anonymous.

CHAPTER 4

4. PRESENTATION OF THE CASES

4.1 Group home A

Group Home A is run by an non-profit charity organisation started in 1994 by the parents of people with learning disability, their friends, specialists working in the field of social services and other people who were interested. In the beginning the association directed its activities to the improvement of the living conditions for the residents of the Institution with Residential Care for People with Learning Disability. The main aim of the organisation is to support the process of deinstitutionalization in the field of social services as a means of integrating disabled people into a natural social environment and to provide social services within the community (website of the organisation). That is the subject of the Project of Sheltered Living for People with Learning Disability which is referred to as Group Home A in this study. Group Home A is intended for people with mental retardation to provide them with permanent home, the necessary assistance and special services.

Residents

Group home A has 12 residents. Except for one resident who has schizophrenia others have mild to profound intellectual disabilities with or without conditions of epilepsy. The residents are more than 35 years old. For this study 8 residents who took part in filling the choice questionnaire, had mild to moderate intellectual disabilities. The residents, the parents, the assistants who run the group home and the administration people of the group home decide what is best for the resident. Residents do have a say about where they want to live and their choices are considered. Residents have the freedom to choose whom they would like to share their room or unit with. Residents can have pets. They can take help from the staff and take care of them.

Assistants/staff

Group Home A is looked after by 12 staffs. Out of these 12 staffs 7 of them take turns in staying in the group home, getting the residents involved in the running of the group home. Duties of the assistants are as follows:

- Each staff is made in charge of 2-3 residents. But in case of emergency the residents can approach anyone of the staffs.
- Monitor the residents and help them run the home. Involve the residents in all the activities of the home.
- Prepare the individual plan with the resident and their parents.
- Take them for outing, if the residents wish to.

Infrastructure/ House hold appearance

Group home A is a completely furnished independent bungalow with independent rooms for the residents and all residents have the key to their rooms. Only two of them share a room, but still both of them have separate keys. Residents have their own television and any kind of electronic gazettes in their rooms. Inside the rooms the residents arrange their belongings the way they wish. Within the group home there is an independent living apartment, but the residents who live there use the common kitchen and dinning for their meals and drinks. Group home has a common living room with a television and music system, an iron and a laundry. The group home is properly furnished and centrally heated. Next to the home within the same campus there is a workshop where the residents work. On top of the workshop and behind the group home there are 2 independent flats. These were constructed because the service providers wanted to try out different models of accommodation for their residents who could live independently.

Employment or daytime activity

One of the residents works in a pub and gets his wages like a normal individual. Two residents go and work 2 days a week in the community. The group home has made an arrangement with the local authority to engage them in the cleaning of the community with the others. They too get paid on hourly basis. Another resident goes and works in a nearby

farm. For the rest of the residents the group home has a sheltered working unit next door. Residents get paid for their work.

Group Home A's Sheltered Workshop

Production of pickled camembert-type cheese:

The sheltered workshop within the campus of the group home A was established to provide work for people who were unable to work in standard working conditions. The production programme in the sheltered workshop specializes in preparing pickled cheese of the camembert type for several cafés and restaurants in Prague.

Personal appearance

The families take care of the clothing. But if the residents feel they need to buy anything they go and buy with some help from assistants. The residents choose the clothes they wish to wear everyday. The assistants take care of the daily personal appearance of the residents and supervise them if they need help in their grooming. All the inmates have their hair cut done when they go and visit their family.

Leisure

They have the same holidays like others. If the residents want to take an off on a working day, they can, but the staff discuss it with the residents if it prolongs. Their choice to go out in the evening or on a weekend is respected and planned with the assistants. The residents of the group home can go out to the place they want with their assistant when their turn comes.

Relationship

The residents are allowed to have relationships. The assistant do have a close watch on the relationship and interfere only when required and when the residents cannot handle the situation.

Meals

The home has a big dinning table and all of them eat together. When the group home was started the assistants made a list of food items the residents would like to have for each week.

Over a period of time, it was found that the residents preferred same kind of food, so they stopped making the list every week. But resident's choices are respected, if they would prefer anything new.

Daily Routine

By 9 they should have their breakfast. After that the residents go and work. They have a break between breakfast and lunch after which they continue their work again. Later in the afternoon they have free time and early evening they have their supper. The residents are expected to be in bed by 10 in the evening. In bed does not mean that they should sleep by 10, but they should not disturb other residents. But they are free to stay awake till anytime.

Maintenance/Running of the group home

The staff involves the residents in the maintenance of the group home except for buying groceries. The home has a timetable for the day with respect to food, work and leisure. It is not rigid, but it is done to structure the day for the residents. There is a time table for all the residents, regarding who is in charge of the kitchen, laundry and cleaning every day.

4.2 Group home B

Group Home B is one among the many projects run by a non-government organisation in Prague. The organisation caters to the needs of people with disabilities from an early age to adulthood in all the areas of their needs. The organisation provides educational services, ergotherapy, advisory services, supported employment, protected housing and free time activities. The protected housing runs 3 projects and one among them is the Group Home B. Group home B is a family-type facility with augmented assistance services. They render services to adults with severe intellectual and other disabilities. The group home was started by parents of children with disabilities, who were studying in the special school run by the same organisation 6 years before. From then on, the same numbers of residents have been residing in the group home (website of the organisation). This group home was a parent's initiative.

Residents

There are 14 residents in group home B. 6 residents among this 14 took part in this study. About one half of the residents are immobile and adults with intellectual disabilities. Here the residents are referred to as clients.

In the home out of the 14 residents 8 of them are legally capacitated and they can decide for themselves. For the rest of the residents by law the parents are held responsible for taking decisions on behalf of the residents

Assistants

Group home B has 9 staffs which include a cleaner too. Everyday 2 staffs stay during the morning, 3 during the afternoon, 1 during the night and 1 stays near the phone during night time to attend to emergency. During the weekends the staffs have a 12 hour shift. Each staff is in charge one room, with 3 residents. Residents if they wish can share their private issues with the staff. Except for the head of the group home none of the staffs are trained in special education.

Household appearances /Infra structure

The residents live in rooms with three beds each and the home have a common dining room, living room and separate rooms for art therapy, ergotherapy and physiotherapy (with a massage tub) and a vast garden/lawn for the residents to relax. The group home can accommodate 16 residents. Out of these 16, one accommodation is kept for respite care. The residents have their personal belongings in their room and arrange their room according to their wish. Group home B is a completely furnished bungalow with all the required facilities.

Employment or daytime activity

Few residents from the home go to the Special School for rehabilitation services/classes and few others to the Centre for Social Education which is a day-care type institution with regular daily work therapy. The centre is for adolescents with medium and severe handicaps those who have either finished compulsory schooling or have graduated from a practical school but have not found work due of their disability. Here the person with disability gets life-long education programme. Some residents make use of the Centre as a therapeutic schooling

facility and, after few months or years of training they go for jobs in the community and the others (severely disabled or immobile) participate in educational programmes, art therapy, ergotherapy and physiotherapy that are provided inside the group home. The group home has a ceramic workshop where the residents work and make ceramic products, which they sell and raise funds for the running of the group home. Often they conduct exhibition during weekends and sell their products.

Paid Job

Seven of the residents go out for job. Among them only 1 go to a job in another village while the others work in the café run by the organisation. All of them get paid for the job, but the amount depends on the job they perform.

Personal appearance

The residents help each other in the areas of self-help. The personal needs of the residents who cannot decide for themselves are taken cared by the parents or family members. The staffs of the home supervise the residents and are of assistance if the residents need help.

Leisure

Residents decide for them selves what they would wish to do in their leisure. During the week end the entire home plan and go for trips. If they do not go out they spend their time in the garden or have a campfire. The staffs plan and prepare leisure activities for residents who need help.

Relationship

The residents are allowed to have relationships and the group of residents who have legal capacitation decide for themselves.

Meals

The staffs prepare the meals for the residents. The residents and the staff made a 5 week plan, which they rotate all through the year, till the residents want to have a change. In

between this plan the residents wish to have anything else, is respected. The group home has a dietitian who looks over the plan and ratifies the same.

Maintenance of the group home

The residents have no job rosters in the group home. Residents clean their rooms but the common places in the group home are cleaned by the cleaner. The staffs and the cleaners take care of the maintenance of the group home. In the evening, the residents volunteer to help if they wish to.

Daily Routine

The residents are expected to get up around 6:30. The group that goes to school and for work should finish their breakfast and leave by 8:45. The group of residents who stay home have a different programme all through the week like ergo therapy, reading, counting, drawing, family education, sex education, swimming, nature study in the garden, physiotherapy, ceramic workshop etc. Each resident has an IVP (individualized planning) planned by the deputy director, the head of the group home and the resident. The staff make short term plans from the IVP, which they carry out on a daily basis.

CHAPTER 5

5. ANALYSIS

5.1 QUANTITATIVE ANALYSIS (t-test results)

For quantitative analysis the total scores and the combined scores of few categories from the choice questionnaire were used. Using these scores different types of t-tests were carried out within group home A and between group home A and group home B.

5.1.1 within Group Home A

Comparison of scores between the residents and the staff

Analysis is done between the self-report scores of the residents and the scores of the staff. Test carried is paired t- test one tailed.

Null Hypothesis:

The Residents self- evaluation is same as the staffs' evaluation of the residents.

Alternative Hypothesis:

The residents self evaluation is better than the staffs' evaluation of the residents.

To check the hypothesis within Group Home A, the residents and staffs mean scores of the choice questionnaire were subjected to paired t-test (t-test for difference of means for dependent samples) with a level of significance of 99%.

Results:

The test result ($p=0.002874$, $df=6$) rejected the 'null hypothesis' thereby accepting the Alternative hypothesis,

> 'The residents felt they experienced more choice in their daily activities in the group home than what the staff felt regarding the residents'.

Combining the categories in the choice questionnaire (group home A)

The choice questionnaire has 6 categories, a total of these give the choice score. The 6 categories are,

1. Domestic activities, staff and the other people you live with
2. Money and spending
3. Health
4. social activities, community access and personal relationship
5. work/ day activities
6. overall choice

Since the questions in few categories are interlinked I did the analysis by combining the categories which were related. As the questions in the "Health" and "overall" categories were different from other categories, these could not be used for combining with other categories.

The categories were combined in combination of two and paired t-test one tailed was carried out for the same.

The categories that were combined were as follows:

- Money and spending was combined with social activities, community access and personal relationship (This was combined on the basis that, to lead a social life and to socialize in the society/community a person needs money)
- Domestic activities, staff and the other people you live with was combined with social activities, community access and personal relationship (This was combined on the basis that a persons domestic and social activities makes him complete)

Results:

- Money and spending and social activities, community access and personal relationship:

Paired t-test with this combination yielded p=0.003437(df=6) rejecting the null hypothesis and accepted the alternative hypothesis, which states,

> "The residents felt they experienced more choice in the group home than what the staff felt regarding the residents with respect to Money and spending and social activities, community access and personal relationship"

- Domestic activities, staff and the other people you live with and social activities, community access and personal relationship

Paired t-test with this combination yielded p=0.021264 (df=6), accepting the null hypothesis, which states,

> "The residents evaluated themselves in the same way as the staff evaluated the residents, with respect to Domestic activities, staff and the other people you live with and social activities, community access and personal relationship"

Comparison of the scores of the staff regarding the present situation and ideal situation they wish to have in Group Home A.

Analysis between the scores of the staff when asked to score the same choice questionnaire for what is happening in the present and what they would prefer to happen as a person, in the group home with respect to choice availability to the residents. Test carried is paired t- test one tailed.

Null Hypothesis:

The staffs are satisfied with what is happening in the group home.

Alternative hypothesis:

The staff feels that there is lot more to improve in the functioning of the group home with respect to choice availability to the residents.

To check this hypothesis t-test for difference of means for dependent samples with a level of significance of 99% was carried out with the staff scores from the choice questionnaire.

Results:

The test result (p=0.02551, df=8) accepting the 'null hypothesis' which states that,

> "The staffs are satisfied with what is happening in the group home".

5.1.2 Between Group Home A and Group Home B

The self-report scores of the residents form Group Home A and Group Home B were analysed. Test carried is t-test for different of means for independent samples.

Null Hypothesis:

There is no difference is evaluation between the scores of the residents from group home A and group home B.

Alternative hypothesis:

The self report scores of the residents from both the group homes are different.

To check this hypothesis between the scores of the residents of Group Home A and Group Home B t-test for difference of means for independent samples with a level of significance of 99% was carried out.

Results:

The test result (p=0.530523, df=12) accepting the 'null hypothesis' which states that,

> "There is no difference is evaluation between the scores of the residents from group home A and group home B".

5.2 QUALITATIVE ANALYSIS

The quantitative study brought to picture only the degree of choice exercised by the residents in the 2 group homes. But this opportunity of getting the questionnaires filled by the residents and staff in the group home was used to do qualitative study of the 2 group homes, as they differed in their background. The qualitative study through unstructured interviews and unstructured observation brought to focus few unique characteristics about each group home and answered few questions which the questionnaire could not do otherwise.

This study would be incomplete if those differences are not brought into focus. And an effort has been made to bring these differences to light in this study.

Three aspects were focused in this study and different methods were used

1. The 'choice questionnaire' was used to find the degree of choice exercised by the people with intellectual disabilities in their respective group homes.
2. Observation of the group home was done whenever I went to the group home for getting the choice questionnaires answered, to find out how the group home was set and organised and how was the group home atmosphere?
3. Unstructured interview with the head or the staff was used to gather qualitative information about the group home like, the running of the group home, the involvement of the residents in the same, their daily routine, and various issues they experienced.

The study found out difference between the two group homes with respect to

a. History of the organisation/group homes
b. Past history of the residents
c. Legal rights of the residents
d. Running of the group home
e. Residents having a say in the selection of staff
f. Staffs in the group home
g. Parents involvement
h. Getting a job in the community
i. Home visits by residents

Both the settings are unique in their own way and they prove to be a good model for a group home, where the welfare of the residents are given priority and all the plans are worked around them irrespective of the residents ability and involvement. Group home A has been running for the last 4 years and the group home B has been running for the last 6 years. It is amazing to see these models of group homes after 10 years following the collapse of the communist rule.

History of the organisation/ group homes

Group Home A

Although the organisation that runs the Group Home A was initiated by parents and well wishers of children with intellectual disability and few specialists, presently it is no more a parent organisation, but a social organisation, run by service providers who are not parents. The service providers are social workers and specialists. Main aim of the organisation is to make people with intellectual disabilities as independent as possible and try out different kinds of accommodation for their residents.

Group Home B

Group Home B is completely a parent initiative and the main focus is to provide a better place to live for their wards, as the parents found it difficult to provide the required services at home. All measures are taken to provide a comfortable accommodation for their wards. The group home is run by one of the parents. In group home B the staffs look after the residents and the residents major decisions are either take by themselves (group that has the legal capacitation) or by/with the parents.

'Parents decide for the residents. Parents are responsible by law.'

Past History of the residents

Group Home A

In group home A the residents were initially living in large institutions or with their parents or in some other organisations. The residents of group home A are middle aged people and most of them have had, experience living in large institutions. According to one of the staff the residents are happy living in the group home. Following describes the previous experiences of the residents in institutions, which the staff shared during the interview.

'Also from my experience and also from what families say, more handicapped people lived to themselves, they spent days rocking somewhere, sitting there.'

'...only the capable ones where cared for and trained for work or they helped the workers of the institution.'

'.....said that her brother was drugged and he was always sleeping. (One of the residents' sister shared this with the staff)

Changes in the life of the residents

The staff felt that the over all quality of life of the individual has improved after coming to the group home.

"They feel much much free here" (Staff interview).

One of the residents from the group home A, who was previously in an institution doing nothing is happy to go and work in the work shop.

'This resident always likes to be at home but now a days he like here.'

Group Home B

In group home B the residents moved directly from home after finishing their school, as the parents found it difficult to meet their son's and daughter's needs in the house. The residents have been living here for last 6 years and they are in the age group of 18-25 years. These residents have never had any experience living in an institution and most of them have studied in a special school. Thereby most of these residents are empowered and aware of their rights and are able to make decisions on their own.

Legal Rights:

Group Home A

In group home A

'.....the residents who were staying with their parents and who later moved into the group home have complete legal rights and those who came from institutions have no legal rights.'

But the parents of the residents who have complete legal rights prefer to have partial legal rights for their wards so that they could be protected. So the group home is trying for partial legal rights for all their residents, which would empower the residents and help them live in other kinds of less supported community living with much less supervision.

Group Home B

In group home B out of the 14 residents 8 of the residents have legal rights to make their decisions.

> *"Out of the 14 clients 8 can do everything by themselves-by the meaning of law. They can make decision on their own, handle money, they can vote."*

Among these 8 residents 6 of them participated in this study. For the remaining residents parents are the legal guardians.

> *'Parents are responsible by law.'*

Running of the Group Home:

Group Home A:

The staff works out the roster for the residents and help them carryout the task. Although the staff does the majority of the work, they make sure that they involve the residents in the routine/plan of the day. Every day, out of all the 12 residents 2 of them stay in the group home and help the staff. Group home A does not have any cleaners for cleaning.

> *'Everyday we (staff and the residents) clean some part of the house. So through the week we go round the house.*

> *'Three of them do their laundry every day. We help few residents and supervise and help them do the laundry and for 2 of our inmates we (the staff) do the laundry.'*

Group Home B:

There are no rosters for the residents for the running of the group home. The residents take part if they wish to. Because the group home have residents who have mobility issues, the residents help each other during the morning tea and breakfast time. The residents, who are capable of taking part in household activities, volunteer to help the staff and cleaners in maintaining the group home. They do it in the evening when they return from job

> *'For laundry, there is a basket and the clients drop their clothes in that and cleaners do the laundry. Clients do not do their laundry.'*

'Clients clean their own room, other common rooms cleaner does.'

'Ironing-cleaner does, but some clients help in the evening.'

'They help with the food, prepare the snacks and help other clients.'

Both the group homes do not involve the residents in planning and buying the groceries although they do the planning of the menu together. When asked about involvement of the residents in all the aspects of running of the group home, the head of the group home B shared that it looks good in the theory but in reality, it does not happen the same way. But he did feel that,

'Of course it can be more involved. It should not be compromised.'

In both the group homes if the residents wish to they are free to get involved in any aspect of the running of the group home.

Residents having a say in the selection of staff

Group Home A

The heads of the organisation choose the staff and the residents have no say in the selection of staff with whom they are going to live with.

'Residents have no say about the recruitment of staff. The person who runs the group home decides which staff would stay.

Group Home B

The committee of parents, trustees and other stakeholders choose the staff.

The head of the group home shared that

'...as the pay of the staff is less, most of them leave the job when they find a better offer, but still after choosing of the staff, the staffs are in the group home for a probationary period of 3 months. During that period if the residents are unhappy with the staff performance they voice out their issues and thereby the residents have a say indirectly.'

Staffs in group homes

In both the group homes the staffs were requested to fill the same choice questionnaire on be half of their residents, so as to obtain the staffs perspective about the residents.

Group Home A

In Group Home A as the staffs shared a very close relationship with the residents; they seemed to know about the residents and were able to fill the questionnaire.

> *'We have clients we over look. I have 2 of them to take care. Other than helping out with their organization, like helping them arrange things and belongings, every month one day one of them have a day out with me. They can choose where they want to go and we go together. We go around or shop or go to a cinema. I feel it is a very positive effect. That day you are for one person.'*

The group home has a standard form for IVP and the staff plans the IVP along with the residents. This is later discussed in group with the other staffs, the parent and the head of the group home.

Group Home B

In Group Home B although the relationship between the staffs and the residents were friendly and warm, the residents were close to their parents and the parents were held responsible for making decisions for the residents. Because of this the staffs felt that they did not know much information about the residents to fill the questionnaire on behalf of the residents.

> *'The staffs felt they didn't know about the clients or they don't have a say regarding the clients so they didn't know what to fill in the questionnaire.'*

Each staff is in charge of 3 residents in the home.

> *'They discuss some private stuff.'*

The residents and staff discuss some private issues.

Parents' involvement

Group Home A

In group home A the head of the organisation, the staffs, the parents and the residents have a say in the plan that is made for the residents. Although all share their ideas regarding the running of the group home, the final decision is taken by the head of the group home checking on what the majority wants and what he/she thinks as feasible.

Group Home B

In group home B any kind of decision regarding the group home need to be discussed with all the parents and only those decisions which all the parents agree can be executed.

> *'In the group home parents have a say in anything new we wish to execute, like having a pet'*

Group home B has a committee which involves director of the organisation, head of the group home, few parents and some residents. The head of the group home shared the following regarding the involvement of the parents in the past and present.

> *'It used to be better with the parents in the beginning, because they were included in the life of the group home'.*

> *'...now they are not interested. Now they just pay and expect the group home to take care of them. Now as there are bigger offer of services, they choose their services. If not satisfied, they can put the child else where.*

The head felt that

> *'Parents don't have a personal relationship with the group home now.*
> *If it is not good they will take him/her(the resident) to another group home.'*

One example he quoted was this, that

> *'I asked the parents to fill the questionnaire.*
> *They said they don't want to as they don't know what to fill in.'*

Getting jobs in the community

Group Home A

Group Home A is looking forward to

'Employ more people in the open market/find more places in open market

(or)

Have another work shop/need to start a new work shop'

Group Home B

In group home B, when residents were tried to be placed in mainstream jobs, it was found that

'....the companies are not prepared to employ a person with physically disability

The companies do not have the working condition for them. But slowly the situation is changing'

Presently the residents, who work in the café run by the organisation, distribute lunch to the nearby old age home. In future, the organisation wants to extend these services to the nearby villages too. This will promote integration into community.

Home visits by residents

Group Home A

All the residents' families are in contact with their wards. Residents make regular weekly visits to see their parents. Either the residents travel home themselves or their parents come and take them.

Group Home B

Not all residents go home every week. Few go every week or twice a month or once a year. It depends on whether the house has the facility and the family can take care of them. The residents decide by themselves whether they want to go home or not. Either the residents travel home themselves or their parents come and take them. Not all residents go home every week. Few go every week or twice a month or once a year. This depends on whether the house has the facility and the family can take care of the residents.

'More or less half the number of the clients go home every week.'

'Some go regularly and some don't-depend on the communication with parents'.

CHAPTER 6

6. DISCUSSION

Choice is widely regarded as an essential component of quality of life (Stancliffe &Parmenter, 1999). O'Brien (1987) as cited in Stancliff and Parmenter (1999) listed choice as one of the five accomplishments essential to quality of life, and other conceptualizations of this construct also feature choice-making as an essential component (Hughes et al. 1995 as cited in Stancliff and Parmenter, 1999). In this study an effort has been made to find the degree of choice exercised by residents of the group home with people with intellectual disabilities using the standardized choice questionnaire (Stancliffe & Parmenter, 1999). T-test was carried using the overall choice scores scored by the residents and the staff of the group home. The paired t-test carried with in the group home A between the choice scores of the residents and the staff rejected the null hypothesis showing that the residents felt that they experienced more choice in their day-to-day living in the group home than what the staff felt the residents experienced. When few categories namely

- Money and spending and social activities, community access and personal relationship (This was combined on the basis that to lead a social life and to socialize in the society/community a person needs money)
- Domestic activities, staff and the other people you live with and social activities, community access and personal relationship (This was combined on the basis that a persons domestic and social activities makes him complete)

were combined, paired t-test on Money and spending and social activities, community access and personal relationship rejected the null hypothesis and accepted the alternative hypothesis showing that, the residents felt they experienced more choice in the group home than what the staff felt regarding the residents with respect to same. Differences between self-reports and proxy responses can be interpreted not as a sign of unreliability in either data source, but as indicating different perceptions by the two groups (Stancliffe 1999 as cited in Schwartz & Rabinovitz, 2003). The observation and interview with the staff, showed a positive atmosphere in the group home and a healthy rapport between the residents and the staff. As most of the residents of group home A previously stayed in large institutions they seemed to

enjoy their freedom and privacy they experienced in the group home. This could be one of the reasons why the residents scored more than what the staff scored for the residents.

The interview and observation showed that both the group homes support the service users (residents) in making choices about their lives by encouraging them to understand their situation, the option they face and helping them to act in their own interest both in small everyday matters and in such important issues as who to live with and what type of work to do as referred by O'Brien & Tyne (1981) cited by Emerson (1992) as cited in Gates, 2003, pg. 55.

Usually, houses with approximately 12-30 people were often referred to as 'half-way houses' as the services being half way between a hospital and independent community living (Gates, 2003, pg. 86). Although both the group homes could be referred to as half way home, based on their numbers, the residents are treated with respect and all measures are taken to make the residents feel at home. Heron, 1982 (Gates, 2003, pg.86) states that, despite being much smaller than institutions, many of these 'half-way houses' were still very institutionalised, and sometimes continued to perpetuate systems that provided block treatment and depersonalized form of care. The scores of the choice questionnaire, interview and the observation showed that the residents felt they had freedom to decide for themselves and their decisions were considered and respected. In group home A we can see the residents scoring more than what the staff scored for the residents regarding the degree of choice. In both the group homes, namely the one run by social workers and specialist and the other run by parents, the residents did not show any difference in the degree of freedom that was available for making choices in their day to day living in both the homes.

In the past, disabled people were segregated from society so effectively that their very existence was completely forgotten by many non-disabled people in the 'outside world' (Included in society). Presently in these group homes the residents' regular visit to see their parents and family members, monthly and weekly outings and yearly trips to different places showed a positive shift. The interview and observation provided enough evidence to support

the efforts taken by service providers to make the residents a part of the community, using community resources.

Daily routine of the residents in both the group homes follow the principal of normalisation. All the residents performed all day's activity similar to a person without disability which included patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society' (Nirje, 1980 as cited in Brown and Walmsley, 1997): in short providing for 'an ordinary life of society' (King's Fund Centre, 1980 as cited in Brown and Walmsley, 1997). When implementing the principal of normalisation, stakeholders must be very clear about the meaning of normalisation,

> "... normalisation does not mean normalcy; it does not mean that people should be normalised... normalisation means the acceptance of a person with their handicap within 'normal society' "(pp. 69–70). (Culham & Nind 2003)

The observation and interview with the staff of both the group homes revealed that the residents of the group home A are more involved in the running of the group home than the residents in group home B. Group home A has a roster for the residents and the staff for the daily maintenance of the group home which group home B does not have. This could be because; most of the residents in group home A worked in the workshop next to the group home and did not work in the community. Further the residents in group home A never had any kind of earlier experience with a working routine in their previous institutions. On the other hand most of the residents in group home B went to work to a different place all through the week. Because of this the residents did not spend much time in the home like the residents in group home A.

Few of the residents from both the group homes work in the community and the service providers of both the group homes are trying to find more opportunities in the community for their residents. In Group home B the residents who work in the café run by the organisation go into the community and distribute lunch to people in old age home. In group home A few of the residents work in the community with the local people. Both the group homes make

conscious effort to integrate the residents in community activities and jobs. Deinstitutionalisation offers hope of allowing people an opportunity to be part of their community (Gerard Quinn, 2006). Persons with intellectual disability should be encouraged to contribute to their communities in order to enhance society's perception of them as valuable community members (Barbara & Siska, 2006).

A focus group study carried by McConkey et al. 2004 with 180 adults intellectual disabilities across Northern Ireland half of whom were living with family caregivers and the rest in a range of other types of accommodations, four personal preference themes common to all participants irrespective of where they lived emerged: having their own bedroom; participating in household activities; having access to community activities; and maintaining contact with family and friends (Barbara & Siska, 2006). In both the group homes the residents had their own bed and personal space, had freedom to take part in household activities though group home A had a roster and group home B did not have one, and made regular visits to see their family and friends.

The head of group home B shared that finding qualified staff to work with people with intellectual disabilities is very difficult as the pay is very low. Barbara & Siska, 2006, argues that because of low value attached to working with individuals with disability makes recruitment of staff with appropriate skills difficult. Staff generally lack training in working with people with ID, as there has been no tradition of this type of training in the Czech Republic.

The European Day of People with Disabilities 2005: 'Living Together in Society' stressed on a "person centric" approach with respect to people with disabilities which reinforced value of citizenship, whereby service recipients are clients not beneficiaries. In both the group homes the residents were referred to as "clients" and personalized services were provided according to the needs of service users, namely the clients. Adding to this, the individual plans that were made for the clients were discussed with them and the parents which I see as a stepping stone towards improved dialogues, especially between the service providers and clients.

In both the group homes although the residents were involved in the planning of IVP and their wishes were heard, in group home A the heads of the organisation made the final decision after discussion with the staff and parents. In the regular monthly or term meetings with the parents and staff, the residents were not involved. Observation and interview with the staff showed that the heads of the group home made the final decisions about every aspect of the running of the group home A. In group home B all decisions need to be discussed within the committee. As parents were legally responsible for half the number of residents and the home being a parent initiative, parents had an influence in the decisions regarding the group home. Though the residents in both the group homes seemed to lead a happy life, I see an urgent need to educate or re-train service providers, enabling them to reach a different understanding of service provision. During the European Day of People with Disabilities 2005: 'Living Together in Society' conference it was pointed out that until this happens, service providers will continue to believe they are providing what is required, to the standards required, as and when required.

The head of the group home B felt that when the group home was started 6 years before when community based services like group homes were starting, all the parents invested lot of time in the running of the group home. Lately as more similar services are available, ownership of the parents has decreased. Further with the new legislation 'act 108/2006 sb' the head of the group home felt it will become more of a business and therefore more impersonal and fears that the human touch would be lost, which I personally feel is a very important factor in any community based services.

6.1 Recommendation for the group homes

Although the research findings depicted a positive picture about both the group homes, more personal involvement of the residents in all the day-to-day activities of the life can enrich their life more. This can happen only through a conscious effort from the side of the service providers. By making the residents experience all aspects of day to day life in which every able individual involve themselves, the residents would feel more responsible for their own life. This will for sure improve their self-esteem and indirectly their quality of life as they will learn to have control on their life decisions.

CHAPTER 7

7. CONCLUSION

7.1 A critical evaluation of the work undertake, including methods and possible areas of further enquiry.

This study is on community based alternatives namely group homes for people with intellectual disabilities in Czech Republic. It focuses is on 2 different service providers namely

- social workers and specialist in the field of disabilities
- parents who wanted their wards to have a good living situation for the rest of his/her life.

This qualitative cum quantitative study has used interview, observation and standardized choice questionnaire (Stancliff and Parmenter, 1999) as the tools for data collection. The study was a learning process about setting a group home for people with intellectual disabilities, who need help in making decisions. The study involved people with intellectual disabilities (mild and moderate) who lived in the group homes and one staff from each group home. Because of the time constrain and language barrier all the stake holders could not be involved. Thus future inquiry should consider involving other stakeholders in their research. Present study gathered information on the degree of choice exercised by people with intellectual disabilities during their day to day living in the group home, history, philosophy, daily routine of the group homes. Additional information like, how the group home is set and organised and is there anything unique about the group home's that was run by 2 different service providers. Since the standardized choice questionnaire (Stancliff & Parmenter, 1999) had its own limitations I focused my study on people with mild and moderate intellectual disabilities and not on people with profound and severe intellectual disabilities, which could be considered in the next study.

The findings showed that both the settings were unique in their own way and they proved to be a good model for a group home, where the welfare of the residents were given priority and all the plans were worked around them irrespective of the residents ability and involvement.

Efforts were made not to minimize assistance, but rather to minimize the creation of dependence. Both the group homes followed the principle of normalisation and advocated the maximization of individual's abilities and choices. This study has been a successful one because of two things.

1. It is amazing to see these models of group homes after 10 years following the collapse of the communist rule in Czech Republic
2. Learning experience I had while carrying out the study.

7.2 Implications of my research findings.

This study was carried out keeping in mind how similar kind of group homes can be planned and set in India for people with intellectual disabilities. In this study I have learnt about the implications of institutionalisation and the importance of Normalisation and what does "Normalisation" exactly mean when it comes to people with disabilities. This study on group homes was a learning experience for me about the areas that need to be considered while setting up a group home for people with intellectual disabilities. Although both India and Czech Republic differ in their culture, tradition, facilities available and attitude of people towards disabilities, in India, disability issues in particular, in the area of community based alternatives are in the process of getting legalized which is a very similar situation in Czech Republic. In this regard both the countries share the same platform in the process of implementation of the policies. The learning from this study would be used for implementing group homes for people with intellectual disabilities in India.

CHAPTER 8

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Appendices

Appendix 1

YAHOO! MAIL

Print - Close Window

From: "nationaltrust" <nationaltrust@nic.in>

To: geethageetha2000@yahoo.com

Subject: Re: greetings from Geetha

Date: Mon, 17 Jul 2006 17:45:55 +0530

Dear Geeta,

Great to know that you are about to finish your course.
I would very much like to hear from you about the
residential set ups in Europe & specially your thesis on
Group Homes in Cezch.

In India, the situation is very dismal. We need to create
something vibrant. But perhaps what is worth looking at
is the Group Homes run by Swayamkrushi in Hyderabad
- by Mrs. Manjula Kalyan - her email i.d. is:
http://us.f310.mail.yahoo.com/ym/Compose?To=ramani_420@yahoo.com&YY=86725&y5beta=yes&y5beta=yes&order=down&sort=date&pos=1
and
http://us.f310.mail.yahoo.com/ym/Compose?To=swayamkrushi@hotmail.com&YY=86725&y5beta=yes&y5beta=yes&order=down&sort=date&pos=1
& Champion Hill in Bangalore by Ananthi & Francis - Dr. Veera
is training there - she can give you a good idea & address etc.

All the best, will get in touch if I find anything else.

Fond Regards,

Poonam.

----- Original Message -----
From:
<http://us.f310.mail.yahoo.com/ym/Compose?To=geethageetha2000@yahoo.com&YY=86725&y5beta=yes&y5beta=yes&order=down&sort=date&pos=1>
To:
<http://us.f310.mail.yahoo.com/ym/Compose?To=nationaltrust@nic.in&YY=86725&y5beta=yes&y5beta=yes&order=down&sort=date&pos=1>;
<http://us.f310.mail.yahoo.com/ym/Compose?To=poonatish@yahoo.com&YY=86725&y5beta=yes&y5beta=yes&order=down&sort=date&pos=1>
Sent: Thursday, July 13, 2006 8:39 PM
Subject: greetings from Geetha

> Dear Poonam,
> how are you? I am doing fine. I am in my last part
> of my Masters Program. Rite now am in Prague doing my
> Thesis on Residential setups in Europe and in
> particular Group homes in Cezch Republic.
> I need some information regarding the models of

> group homes we have in India. I went through the
> National Trust website and saw the Samarth Scheme. i
> was very disappointed. But i would like to know more
> about the history of residential setups in India with
> respect to disability and about the present situation
> aswell.I discussed about this with Sudha and she asked
> me to mail you and check with you. any kind of
> information or website would be of great help.
>
> My course is getting over on 28th of august with my
> viva. i have booked my tickets for 30th august.waiting
> to see you all soon.
>
> Awiting your reply.
> Thanking You.
> With love and regards,
> Geetha
>
>
> _____
> Do You Yahoo!?
> Tired of spam? Yahoo! Mail has the best spam protection around
> http://mail.yahoo.com/

Appendix 2

geetha123_aqua@hotmail.com Printed: Thursday, July 27, 2006 8:57 PM

From : <Marketa.Holeckova@mpsv.cz>
Sent : Tuesday, July 25, 2006 5:47 AM
To : <geetha123_aqua@hotmail.com>
Subject : RE: Referred by Dr. Jan Siska (Charles University)

108/2006 Sb.
benefits go directly to users (NOT TO FAMILY - family is the possibilityy who can give the support)
Inspection of social services control at the level of MINISTRY and REGIONS - 3 parts of the act - one is quality (standards of quality). than duties and the last one is the registration of providers

Marketa Holeckova
-----Original Message-----
From: geetha muralidharan [mailto:geetha123_aqua@hotmail.com]
Sent: Thursday, July 20, 2006 12:08 PM
To: Holeèková Markéta (MPSV)
Subject: RE: Referred by Dr. Jan Siska (Charles University)

Dear Holeckova,
hope you are having a nice vacation. i am very sorry to disturb you during your vacation time. In this mail i have sent you what you told me about the 'Act 108/2006 sb'. I would appreciate if you can go through what I have written and acknowledge back that these are the information you shared with me in my interview.This is important because this information on Act will be cited in my thesis.
You can reply me in this mail. If any correction is required or any other information needs to be included or removed please let me know.

After 13 years in Czech Republic ¡§Act 108/2006 sb¡¨¡¨ has been passed, which is expected to be implemented from January 2007. Main features of this act being:

• Benefits of social services from the ministry will go directly to the users and their family members. Depending on the degree of disability, the funds will be distributed.

• Regions are responsible for planning the social services. Municipalities will work close to

the community and families where by people with disabilities can approach them for any kind of services.

• Improve the standards of inspection of social services to check quality of services rendered and to improve standards of quality.

• Specifies the duties of service providers and social workers.

The Act over all try to provide equal opportunities to all providers and no differences to social services run by region or municipality or individual keeping in mind ¡§All people are the citizens of equal rights¡¨.(3 rd juiy 2006, interview with Dr. Holeckova, Ministry of social services).

Awaiting Your reply.

Thanking you,
Regards,

Geetha

Appendix 3

The Choice Questionnaire For clients (English)

APPENDIX A

The Choice Questionnaire

Acquiescence and recency items must be "passed". They may be asked before or during the first part of the checklist.

RECENCY ITEMS:

a. Do you live by yourself or with other people? [ ] By myself [ ] With others
b. Do you live with other people or by yourself? [ ] By myself [ ] With others

Actual situation:
Lives alone/with others
(Circle correct alternative)

ACQUIESCENCE ITEMS

Most mornings do **you** pick what clothes to wear? [ ] Yes [ ] No
Most mornings does **someone else tell** you what clothes to wear? [ ] No [ ] Yes.

I DOMESTIC ACTIVITIES, STAFF AND THE OTHER PEOPLE YOU LIVE WITH

SCORING CATEGORIES

	3	2	1
1 Who decides what time you go to bed? (Does anyone **tell** you what time to go to bed? Are there any rules about what time you should go to bed?)	[ ] I decide for myself.	[ ] I usually decide with help. Sometimes others tell me	[ ] I have a set bedtime. **OR** Others mostly tell me when to go to bed.
2 Who decides which jobs **you** do around the house? Do you have set jobs or a jobs roster? Who works out the roster/set jobs?	[ ] I/we (the residents) choose the jobs I/we do.	[ ] I/we (the residents) usually choose with help from staff. **OR** I/we help staff make up the jobs roster.	[ ] Others mostly tell me. **OR** My jobs are set by a jobs roster or list made up by someone else.
3 When **you** cook dinner, who chooses what you cook? Do you ask the others who live here what they would like to eat?	[ ] I choose (I may check with other residents to see what they do/don't like).	[ ] I usually choose with help from staff.	[ ] I don't cook dinner (or I only help with cooking) **OR** Others mostly choose what I cook **OR** There is a planned menu made up by someone else.

4 Can you get yourself a drink or something to eat whenever you want? Any time? Do you have to ask someone first?	[ ] Yes. I can have a drink or snack whenever I want.	[ ] I can usually have a drink or a snack but I have to ask first.	[ ] No. I am not usually allowed to have snacks and/or drinks **OR** I can only have them on special occasions.
5 What rules are there about using the telephone? Can you ring up whenever you want to?	[ ] I can ring up without restrictions whenever the phone is not being used.	[ ] I can usually ring up. I may ask staff first. There may be minor restrictions (e.g. can't talk for too long if others want to use the phone).	[ ] I am unable or not allowed to use the phone **OR** my telephone use is restricted (e.g. only allowed to ring at specified times or to certain places or limited to local calls only).
6 Who picks the staff to work in your house? (Do you interview new staff to decide who will get the job? Are you asked what you think about new staff?)	[ ] I/we (the residents) are responsible for deciding which staff will be employed (e.g. I sit on interview panels).	[ ] I/we (the residents) participate in choosing staff - e.g. I am asked for my views about new staff.	[ ] Others choose the staff I am not consulted and have no real say about who works in my house.
7 Are there any rules in your house? Who makes up the rules for your house? (Do not include rules imposed in the lease or by the landlord.)	[ ] There are no rules (except the landlord's rules in the lease). **OR** I/we (the residents) decide the rules.	[ ] I/we (the residents) decide the rules with help from others.	[ ] Others decide the rules. I have no real say.
8 Do you have your own key to the house? Do staff have keys to your house? Did you give them the key? Who says which people can have a key?	[ ] I have a key. Staff do nothave keys **OR** I/we (the residents) decide who canhave a key I have a fair say	[ ] I have a key, but others mostly decide who else also has a key.	[ ] I do not have a key. I have no real say about who has a key
9 Who decides if **you** can have a pet [like a dog, a bird or goldfish] if you want you have any kind of pet you want. Do you have to ask anyone before you get a pet?	[ ] I can have any pet I like with no restrictions.	[ ] There may be some restrictions (e.g. on the type of pet) because of my lease/landlord. **OR** I have to ask others first.	[ ] I am not allowed to have a pet. **OR** Others decide and I have no real say.

10 What rules are there about you being by yourself in the house [by yourself and **without staff**]? Can you be by yourself in the house if you want to? Anytime? ***If person lives alone score as 3 (i.e. no restrictions).***	[ ] I can be by myself in the house at any time with no restrictions	[ ] Sometimes I can be by myself (e.g. only in certain situations or for short periods - 1 - 2 hours).	[ ] I am not allowed to be by myself. I never am by myself in the house.
II MONEY AND SPENDING			
11 Who works out your budget so you will have enough money?	[ ] I budget my own money without assistance.	[ ] I have help budgeting my money.	[ ] Others budget my money and I have little say. **OR** I have a fixed budget worked out by others.
12 Who decides **how much** money you take out of your bank account? Can you take out as much as you want? Do you ask anyone how much to take out?	[ ] I decide without help and with no restrictions on how much to withdraw.	[ ] I have help to decide how much to take out **OR** I ask someone how much to take out **OR** I have a limit on how much I can withdraw.	[ ] Others mostly decide how much to withdraw and I am not consulted.
13 When you buy your clothes who chooses which clothes to buy?	[ ] I choose. I buy my clothes with no help.	[ ] I usually choose my clothes with help (e.g. someone usually goes with me).	[ ] Others mostly decide **OR** Others buy clothes for me.
14 Do you spend some money on gambling like lottery tickets, lotto, poker machines or the TAB? Who decides that you do/don't gamble? (Can you gamble if you want to?)	[ ] I decide.	[ ] I usually decide with help **OR** Sometimes others may tell me not to.	[ ] I am not allowed to gamble.

III HEALTH

15 Does anyone go with you to see the doctor and the dentist? Who? Does ..... always go?	[ ] I always go by myself or with a friend.	[ ] Staff or family (e.g. parents) come with me to some appointments (e.g. specialists).	[ ] I (almost) always go with staff or family (e.g. parents).
16 Do you drink alcohol like beer or wine? Who decided that you do/don't drink beer/wine? Do you ask anyone if you can drink alcohol? Who? (*If person drinks*: Does anyone try to stop you drinking alcohol? *If person does not drink*: Why is that?)	[ ] I decided. I am free to drink or not.	[ ] I decided with help **OR** I ask someone (staff or family) first **OR** I don't drink because of the medication I take or other medical reasons **OR** I drink but there are some restrictions on my drinking.	[ ] Others decide (e.g. say I am not allowed to drink).
17 Do you do exercise or play sport? Who decides that? (Does anyone make you do exercise or sport?)	[ ] I decide.	[ ] I usually decide with help.	[ ] Others mostly decide. **OR** I am made to do exercise/sport

IV SOCIAL ACTIVITIES, COMMUNITY ACCESS AND PERSONAL RELATIONSHIPS

18 Does anyone stop you from going out? Is there anywhere you are not allowed to go?	[ ] No-one stops me. I can go wherever I want.	[ ] There are 1 or 2 places I am told not to go to.	[ ] Others often stop me going out **OR** I am not allowed to go to quite a few places.
19 Who decides what you do in your spare time[when you are not working or at day activities]?	[ ] I decide.	[ ] I usually decide with help.	[ ] Others mostly decide.

20 Who decides if you can go to hotels and clubs? (Does anyone try to stop you?)	[ ] I decide.	[ ] I usually decide with help.	[ ] Others mostly decide. **OR** I am not allowed to.
21 Who decides if you can go and visit your family and friends [whenever it is all right with them]? Do you ask anyone first? Who?	[ ] I can visit whenever it's okay with my family or friends.	[ ] I can visit but I ask someone (other than the person I am visiting) first.	[ ] Others decide. **OR** I am not allowed to visit.
22 Does anyone stop you from looking at sexy [X rated] magazines, videos or movies? (If the person says "*I don't look at those things*", ask: Who decided that?)	[ ] No. I can look at anything I want (in private). **OR** I decide not to.	[ ] Usually no-one stops me. Occasionally they may ask me not to. **OR** I decided with help not to.	[ ] I am not allowed to. **OR** I am only allowed to look at things some else says are okay.
V WORK/ DAY ACTIVITIES			
23 Can you leave your job/ day activity if you want to, do no work and just stay at home? Would you ask anyone first? (Would anyone try to stop you leaving if you wanted to?)	[ ] Yes, I can leave if want to. I don't have to ask anyone else. **OR** I have already left my job/ activity & it was completely my decision.	[ ] I participate in the decision and discuss it with others.	[ ] Others decide **OR** I am not allowed to leave **OR** I have never had a job or day activities.
24 Can you be late home from work/ day activities? Do you have to tell anyone first or ring up? (Do you get into trouble for being home late?)	[ ] I can come home whenever I like. I don't have to tell anyone first or ring up.	[ ] I can be late if I want, but I am supposed to ask/ tell someone first or ring up. I get into trouble if I don't tell someone or ring up.	[ ] Others decide. **OR** I am not allowed to be late. **OR** I have no opportunity to stop off after work & get home late because I never go to work/ day activities or because I am driven straight home.

25 What happens if you want to take a day off work/ day activities when you are **not** sick? You just feel like having a day off. Do you have to ask anyone first?	[ ] It is my decision. (I might lose a day's pay).	[ ] I decide with help. I ask others (e.g. staff or family) first.	[ ] Others decide - I have no real say. **OR** I am not allowed. I have to go to work/day activities **OR** I do not make this choice because I never work or attend day activities.

VI OVERALL CHOICE

26 Overall would you say that your life is free so you can choose what you want? All the time?	[ ] Yes definitely.	[ ] Yes, most of the time. Sometimes it is planned for me.	[ ] No. I often cannot do what I want.

APPENDIX B

Choice Questionnaire scoring criteria and procedure

For all versions of the *Choice Questionnaire* all items were scored on a 3-point scale. Specific criteria were provided for each item and were based on the following scoring guidelines:

Score=3
The person makes the choice actively, independently and without restrictions all or almost all the time. For decisions involving other residents, such as what food to buy for the house, this score was allocated if the choice was made by residents collectively according to these criteria *and* the individual participated actively and had a fair say.

Score=2
The person makes the choice some of the time or usually has help choosing. Minor restrictions on choice or having to ask others (e.g., staff) for approval also resulted in a score of 2.

Score=1
Others decide all or most of the time, or the person is not allowed to make the choice.

For the self-report version, the *interviewer* selected the appropriate score on the basis of the person's reply to the question and any subsequent probes. Participants simply were asked to answer questions, not select a point on the 3-point scale. As a staff-report instrument, staff chose the response alternative which most appropriate reflected the resident's situation.

Appendix 4

The Choice Questionnaire For clients (Czech)

Dotazník volby

.Domácí aktivity, zaměstnanci a ostatní lidé,

1. Kdo rozhoduje, kdy má jít klient spát?

Sloupec 1
( ) .rozhoduje se sám klient
( ) rozhoduje se sám klient ale s pomocí
( )klienti mají určený čas,kdy jít spát

2. Kdo rozhoduje,co bude klient v domácnosti dělat?

Sloupec 1
( ) obyvatelé si práci volí sami
( ) obyvatelé si práci volí s pomocí zaměstnanců nebo se účastní spolu se zaměstnanci na sestavení rozpisu služeb/seznamu prací
( ) někdo obyvateli většinou řekne nebo rozpis služeb/seznam prací vytváří někdo jiný

3. Kdo vybírá,co se bude vařit?

sloupec 1
( ) vybírají si sami obyvatelé
( ) při výběru někdo pomáhá
( ) vybírají zaměstnanci nebo někdo jiný

4. Kdo připravuje oběd?

sloupec 1
( ) obyvatelé
( ) obyvatelé s dopomocí
( ) zaměstnanci nebo někdo jiný

5. Mohou si obyvatelé vzít pití nebo jídlo,kdykoli chtějí?Musí se nejdříve někoho optat?

Sloupec 1
( ) Ano, obyvatelé si mohou vzít pití nebo občerstvení kdykoli chtějí
( ) Obyvatelé si většinou pití nebo občerstvení vzít mohou,ale nejdříve se musí optat
( ) obyvatelé si kromě zvláštních příležitostí nemohou vzít pití ani občerstvení

6. Jaká platí pravidla užívání telefonu? Mohou obyvatelé telefonovat kdykoli chtějí?

sloupec 1
( ) obyvatelé mohou telefonovat bez dalších omezení kdykoli není telefon potřeba
( )obyvatelé zpravidla mohou telefonovat po domluvě se zaměstnancem.Platí určitá pravidla(např.nesmí hovořit dlouho,když ostatních potřebují telefonovat také)
( ) Obyvatelé nesmí používat telefon nebo platí omezení (např.nesmí telefonovat v určitý čas nebo na určitá místa nebo může pouze místní hovory)

7 Kdo vybírá zaměstnance?

sloupec 1
( ) odpovědnost za rozhodnutí,kdo bude v domácnosti zaměstnán, nesou obyvatelé
( ) Obyvatelé se účastní výběru zaměstnanců, např. jsou dotázáni na názor na nového zaměstnance
( ) vybírá někdo jiný

8. Platí v domě nějaká pravidla? Kdo je vytváří?

sloupec 1
( ) neplatí žádná pravidla nebo je vytváří obyvatelé
( ) .pravidla vytváří obyvatelé s pomocí zaměstnanců (ostatními)
( ) pravidla vytváří ostatní. Obyvatelé do záležitosti nemluví

9. Mají obyvatelé vlastní klíče k domu/pokoji? Mají zaměstnanci klíče od pokojů klientů? Odevzdávají obyvatelé klíče zaměstnancům? Kdo rozhoduje o tom, kdo může mít klíč?

sloupec 1
( ) Obyvatelé mají klíče a zaměstnanci ne nebo obyvatelé rozhodují, kdo klíč bude mít. Obyvatelé plnoprávně o záležitosti spolurozhodují
( ) Obyvatelé mají klíče,ale většinou ostatní rozhodují,kdo jiný klíč bude mít
( ).Obyvatelé nemají klíč.Nepodílí se na rozhodnutích,kdo klíč bude mít

10. Kdo rozhoduje o tom,zda obyvatel může mít domácí zvíře ?Musí se obyvatelé nejdříve optat?

sloupec 1
( ) Obyvatelé mohou mít domácí zvíře bez omezení
( ) Určitá omezení platí (např.druh zvířete) nebo se obyvatelé musí nejdříve optat.
( ) obyvatelé nemohou mít domácí zvíře nebo o tom rozhodnou ostatní. Obyvatelé se na rozhodnutí nepodílí

11. Jaká platí pravidla o samostatném pobytu obyvatel v domácnosti bez přítomnosti zaměstnanců?Mohou v domácnosti zůstat sami,když si to přejí?Kdykoli?

sloupec 1
( ) .Obyvatelé mohou zůstat sami v domácnosti kdykoli bez dalších omezení
( ) Někdy mohou být obyvatelé sami (např.v určitých situacích nebo po kratší dobu 1-2hodiny)
( ) nemohou být sami

(II) Peníze a použití peněz

12. Kdo připravuje rozpočet, aby měli obyvatelé dostatek peněz?

sloupec 1
( ) obyvatelé si hospodaří s penězi sami bez pomoci
( ) obyvatelé potřebují v hospodaření s penězi pomoc
( ) Hospodaření s penězi dělá za obyvatele někdo jiný nebo mají fixní rozpočet,který za ně někdo stanoví

13. Kdo rozhoduje, jakou částku si mohou obyvatelé vybrat z (bankovního) účtu?Ptá se obyvatel, kolik si má vybrat?

sloupec 1
( ) Obyvatel si sám bez omezení rozhoduje, kolik si vybere
( ) Obyvatel se poradí a rozhodne se, kolik má vybrat nebo se optá, kolik má vybrat nebo má limit, do kolika může vybírat
( ) většinou za něj rozhodnou jiní, bez dohody s ním

14. kdo rozhoduje, jaké oblečení si má obyvatel koupit?

sloupec 1
( ) rozhodují se sami obyvatelé,oblečení nakupují bez pomoci
( ) Obyvatelé si vybírají oblečení s pomocí (např.s nimi obyčejně někdo jde)
( ).většinou za ně rozhodne někdo jiný nebo za ně někdo nakupuje

15. Sázejí obyvatelé peníze, hrají apod.? Kdo rozhoduje o tom,zda obyvatelé mohou hrát?

sloupec 1
( ) rozhodují obyvatelé
( )Obyvatelé se rozhodují s pomocí nebo jim někdy ostatní doporučují, aby nehráli
( ) nesmí hrát

Zdraví

16. Doprovází někdo obyvatele k doktorovi a zubaři? Kdo?

sloupec 1
( ) Obyvatelé chodí sami nebo s kamarádem
( )na některá vyšetření chodí se zaměstnancem nebo s rodinou (např.odborné vyšetření)
( ) obyvatelé jdou vždy s rodinou nebo zaměstnancem

17. Pijí obyvatelé alkohol jako pivo nebo víno?kdo rozhoduje, zda ne/budou pít alkohol? Když obyvatel pije,pokouší se ho v tom někdo zastavit? Pokud obyvatel nepije,proč?

sloupec 1
( ) obyvatelé mohou pít,je to jejich rozhodnutí
( ) obyvatel se rozhoduje s pomocí nebo nejdříve se optá zaměstnance nebo rodiny nebo nepije z důvodu medikace nebo může pít ale platí určitá omezení
( ) rozhodují druzí (např. říkají,že osoba nesmí pít alkohol)

18. sportují obyvatelé? kdo o tom rozhoduje?

sloupec 1
( ) sami obyvatelé.
( ) většinou se rozhodují obyvatelé s pomocí
( )většinou rozhodují druzí.

Sociální aktivity, přístup do komunity, osobní vztahy

19. brání někdo obyvatelům chodit ven? Jsou místa, kam obyvatelé nesmí ?

sloupec 1
( ) nikdo jim nebrání. obyvatelé mohou, kam chtějí
( ) je pár míst,kam by neměli
( )ostatní/zaměstnanci většinou brání jít obyvatelům ven nebo obyvatelé smí na omezený počet míst

20. kdo rozhoduje o volném čase obyvatel?

sloupec 1
( ) sami obyvatelé rozhodují
( ) většinou se rozhodují obyvatelé s pomocí
( ) rozhodují většinou druzí

21. kdo rozhoduje,zda obyvatelé mohou do restaurací, klubů? brání jim v tom někdo?

sloupec 1
( ) sami obyvatelé rozhodují
( ) obyvatelé se rozhodují s pomocí
( ) většinou rozhodují druzí nebo obyvatelé nesmí chodit

22. Kdo rozhoduje, kdy může obyvatel navštívit rodinu či kamarády (když to vyhovuje jim)?Musí se obyvatelé nejdříve někoho optat? Koho?

sloupec 1
( ) obyvatelé mohou jet,kdykoli se to hodí rodině nebo kamarádům
( ) obyvatelé mohou jet, ale musí se nejdříve optat
( ) rozhodují druzí nebo obyvatelé nemohou jezdit

23. Brání někdo obyvatelům číst erotické časopisy nebo sledovat erotické pořady v TV?

sloupec 1
( ) Ne. Obyvatelé v soukromí mohou sledovat co chtějí
( )Obyvatelům většinou nikdo nebrání. Příležitostně může zaměstnanec požádat opačně nebo pomoci obyvateli s rozhodnutím pořad nesledovat
( )obyvatelé nemohou sledovat nebo mohou sledovat to,co zaměstnanci schválí

PRÁCE /DENNÍ ČINNOSTI

24. Mohou obyvatelé odejít z práce(rozvázat pracovní poměr) pokud chtějí, nepracovat a zůstat doma? Musí se někoho optat(bránil by jim někdo v odchodu?)?

sloupec 1
( ) Ano,obyvatelé mohou odejít,pokud chtějí.nemusí se ptát
( ) obyvatelé to prohovoří s druhými a rozhodnou se
( ) rozhodují druzí, obyvatelé nesmí odejít

25. Mohou se obyvatelé vrátit z práce pozdě? Musí to předem někomu oznámit nebo zatelefonovat?

sloupec 1
( ) obyvatelé se mohou vrátit, kdy chtějí aniž by to někomu oznamovali nebo telefonovali
( ) .Obyvatelé mohou přijít pozdě,pokud si to přejí, ale předpokládá se, že to předem někomu oznámí nebo zatelefonují
( ) .rozhodují druzí nebo obyvatelé nesmí chodit pozdě nebo se obyvatelé nemají příležitost po cestě z práce nikde stavovat protože jejich práce je přičleněna k domácnosti

26. jaká je praxe,když si obyvatelé chtějí vzít den volna aniž by byli nemocní? Musí se nejdříve někoho optat?

sloupec 1
( ) je to rozhodnutí obyvatel (mohou přijít o denní mzdu)
( ) obyvatelé se rozhodují s pomocí,ptají se např. zaměstnanců,rodiny
( ) Rozhodují druzí nebo obyvatelé nemohou.Musí jít do práce

Celková volba

27. celkově byste hodnotil/a život obyvatel jako volný ve smyslu, že si mohou zvolit, co chtějí? Vždy?

Option Set 1
( ) určitě
( ) ano,většinou.někdy se pro obyvatele plánuje
( ) ne,obyvatelé většinou nemohou dělat,co chtějí

Děkuji za spolupráci

Appendix 5

The Choice Questionnaire For Staff (English)

THE CHOICE QUESTIONNAIRE

NOTE:
Please choose one choice in each of the option sets 1 and 2.
Option set 1 refers to what is currently happening in the group home
Option set 2 refers to what you as a person and staff in the group home would prefer to happen.
Please use the boxes under the questions to fill-in your thoughts if the choices does not convey what you want.

Domestic activities, staff and the other people you live with.

1. Who decides at what time the client should go to bed?

Option Set 1	Option Set 2
( ) The client decides for himself.	( ) The client should decide for himself
( ) The client decides with help	( ) The client should be helped to decide
( ) The clients have a set bedtime	( ) The client should have a set bed time

2. Who decides which job the residents should do around the house?

Option Set 1	Option Set 2
( ) The residents choose the job	( ) The residents should choose the job themselves
( ) The residents choose the job with help from the staff (or) The resident's help the staff make up the jobs roster.	( ) The residents should be involved/helped in making the roster or list.
( ) Others mostly tell the residents. (or) The resident's jobs roster or list made up by someone else.	( ) The resident's job roster must be made by others.

3. Who chooses the menu for the dinner?

Option Set 1	**Option Set 2**
( ) The residents choose the menu	( ) The residents should choose the menu
( ) The residents are helped to choose their menu	( ) The residents should be helped to choose their menu
( ) The staff or others choose the menu	( ) The staff or others should choose the menu

4. Who prepares the dinner?

Option Set 1	**Option Set 2**
( ) The residents prepare the dinner	( ) The residents should prepare the dinner
( ) The residents prepare the dinner with help	( ) The residents should prepare the dinner with help
( ) The staff or others prepare the dinner	( ) The staff or others should prepare the dinner

5. Can the residents get themselves a drink or something to eat whenever they want? Anytime? Do they have to ask someone first?

Option Set 1	**Option Set 2**
( ) yes. The residents can have a drink or snack whenever they want	( ) yes. The residents should have a drink or snack whenever they want
( ) The residents can usually have a drink or a snack but they have to ask first.	( ) The residents should have a drink or a snack but they have to ask first.
( ) The residents are not allowed to have snack or drinks (or) the residents can only have them on special occasions	( ) The residents should not be allowed to have snack or drinks (or) the residents should have them only on special occasions.

6. What rules are there about using a telephone? Can the residents ring up whenever they want?

Option Set 1	**Option Set 2**
( ) The residents can ring up without restrictions whenever the phone is not being used. ( ) The residents can usually ring up. The residents may ask staff first. There are minor restrictions(e.g, can't talk for too long if others want to use the phone) ( ) The residents are not allowed to use the phone or the telephone use is restricted.(e.g.only allowed to ring at specified times or to certain places or limited to local calls only)	( ) The residents should be allowed to ring up without restrictions whenever the phone is not being used. ( ) The residents can usually ring up. The residents should ask staff first. There should be minor restrictions(e.g, can't talk for too long if others want to use the phone) ( ) The residents should not be allowed to use the phone or the telephone use should be restricted.(e.g.only allowed to ring at specified times or to certain places or limited to local calls only)

7. Who picks the staff to work in the house?

Option Set 1	**Option Set 2**
( )The residents are responsible for deciding which staff will be employed ( ) The residents participate in choosing staff e.g The residents are asked for his/her views about new staff ( ) others choose the staff.	( )The residents should be responsible for deciding which staff will be employed ( ) The residents should participate in choosing staff e.g The residents should be asked for his/her views about new staff ( ) others should choose the staff

8. Are there any rules in the house? Who makes up the rules for the house?

Option Set 1	**Option Set 2**
( ) There are no rules (or) the residents decide the rules ( ) The residents decide the rules with the help from others. ( ) others decide the rules. The residents have no real say.	( ) There should be no rules (or) the residents should decide the rules ( ) The residents should decide the rules with the help from others. ( ) others should decide the rules. The residents should have no real say

9. Do the residents have their own keys to the house/room? Does the staff have keys to the residents room? Do the residents give the key to the staff? Who decides which people can have the key

Option Set 1	**Option Set 2**
( ) The residents have the key and the staff do not have keys (or) the residents decide who can have a key. The residents have a fair say. ( ) The residents have a key, but others mostly decide who else has a key. ( ) The residents do not have a key. I have no real say about who has the key.	( ) The residents should have the key and the staff should not have keys (or) the residents decide who can have a key. The residents should have a fair say ( ) The residents should have a key, but others mostly should decide who else can also have a key. ( ) The residents should not have a key. The residents should have no real say about who has the key

10. Who decides whether the residents can have a pet, if the residents want to have a pet. Do the residents have to ask anyone before they can get a pet?

Option Set 1	**Option Set 2**
( ) The residents can have any pet without any restriction. ( ) There are some restrictions (e.g. on the type of pet) (or) the residents have to ask others first. ( ) The residents are not allowed to have a pet.(or) others decide and the residents have no real say	( ) The residents should be allowed to have any pet without any restriction. ( ) There should be some restrictions (e.g. on the type of pet) (or) the residents should ask others first ( ) The residents should not be allowed to have a pet. (or) others should decide and the residents should have no real say.

11. What rules are there about the residents being by themselves in the house (by themselves and without staff)?Can they be by themselves in the house if they want to? Anytime?

Option Set 1	**Option Set 2**
( ) The residents can be by themselves in the house at anytime with no restrictions. ( ) sometimes the residents can be by themselves.(e.g. only in certain situations or for short periods – 1-2 hrs) ( ) The residents are not allowed to be by themselves.	( ) The residents should be allowed to be by themselves in the house at anytime with no restrictions ( ) sometimes the residents should be allowed to be by themselves.(e.g. only in certain situations or for short periods – 1-2 hrs) ( ) The residents should not be allowed to be by themselves

(II) MONEY AND SPENDING

12. Who works out the budget so that the residents will have enough money?

Option Set 1	**Option Set 2**
( ) The residents budget their own money without assistance. ( ) The residents need help budgeting their money ( ) others budget the money for the residents and they have little say. (or) they have a fixed budget worked out by others.	( ) The residents should budget their own money without assistance. ( ) The residents should be helped budgeting their money ( ) others budget the money for the residents and they have little say (or) they have a fixed budget worked out by others.

13. Who decides how much money the residents can take out of the (bank) account? Can the resident take out as much as they want? Does the resident ask anyone how much to take out?

Option Set 1	**Option Set 2**
( ) The resident decides without help and with no restrictions on how much to withdraw. ( )The residents take help to decide how much to takeout. (or) the resident ask someone how much to takeout (or)the resident have a limit on how much he/she can withdraw. ( ) others mostly decide how much to withdraw and the residents are not consulted.	( ) The resident should decide without help and with no restrictions on how much to withdraw. ( ) The residents should be helped to decide how much to takeout. (or) the resident should have a limit on how much he/she can withdraw. ( ) others shouid mostly decide how much to withdraw and the residents should not be consulted.

14. When the residents buy their clothes who chooses which clothes to buy?

Option Set 1	**Option Set 2**
( ) The residents choose. They buy their clothes with no help. ( ) The residents choose clothes with help.(e.g. someone usually goes with them) ( )others mostly decide (or) others buy clothes for them.	( )others mostly decide (or) others buy clothes for them. ( ) The residents should choose clothes with help.(e.g. someone usually goes with them) ( )others should mostly decide (or) others should buy clothes for them.

15. Do the residents send money on lottery tickets, lotto, porker machines? Who decides that the residents can/can't gamble?

Option Set 1	**Option Set 2**
( ) The residents decide ( ) The residents usually decide with help or sometimes others may tell them not to. ( ) The residents are not allowed to Gamble	( ) The residents should be allowed to decide ( ) The residents should be helped to decide or sometimes others should/may tell them not to ( ) The residents should not be allowed to Gamble

HEALTH

16. Does anyone go with the resident to see the doctor and the dentist? Who? Does ….. always go?

Option Set 1	**Option Set 2**
( ) The resident go by themselves or with a friend ( ) staff or family come with the resident to some appointments (e.g. specialist) ( ) The resident always goes with staff or family.	( ) staff or family should go with the resident to some appointments (e.g. specialist) or all. ( ) The resident should always go with staff or family.

17. Do the residents drink alcohol like beer or wine? Who decides that they do/don't drink alcohol?(If the person drinks: does anyone try to stop them drinking? If the person does not drink: why is that?)

Option Set 1	**Option Set 2**
( ) The residents decide. They are free to drink or not. ( ) The residents decide with help (or) the residents ask some staff or family first (or) the resident don't drink because of the medication (or) the residents can drink but they have some restrictions on their drinking. ( ) others decide (e.g say they are not allowed to drink)	( ) The residents should be free to decide. ( ) The resident should be helped to decide ( ) others decide (e.g say they are not allowed to drink)

18. Do the residents do exercise or play sports? Who decides that?(does anyone make the residents do exercise or sport?)

Option Set 1	**Option Set 2**
( ) The residents decide. ( ) the residents usually decide with help ( ) others mostly decide.	( ) The residents should be allowed to decide ( ) the residents should usually decide with help. ( ) others should decide for them.

SOCIAL ACTIVITIES, COMMUNITY ACCESS AND PERSONAL RELATIONSHIP

19. Does anyone stop the residents from going out? Is there anywhere the residents are not allowed to go?

Option Set 1	**Option Set 2**
( ) No one stops the residents. They can go wherever they want ( ) There are 1 or 2 places they are told not to go to. ( ) others /staff often stop the residents going out. (or) The residents are not allowed to go to quite a few places.	( ) No one should stop the residents. They should be allowed to go wherever they want ( ) The residents should be warned not to go to few places. ( ) the residents should not go out without the staff supervision

20. who decides what the residents do in their spare time(when the residents are not working or at day activities)

Option Set 1	**Option Set 2**
( ) The residents decide ( )the residents usually decide with help ( ) others mostly decide	( ) The residents should be allowed to decide for themselves. ( ) The residents should be helped to decide. ( ) others should decide for the residents

21. Who decides the residents can go to hoteis and clubs? (does anyone try to stop them?)

Option Set 1	**Option Set 2**
( ) the residents decide ( ) the residents should decide with help. ( ) others mostly decide (or) the residents are not allowed.	( ) The residents should be allowed to decide for themselves ( ) The residents should be helped to decide. ( ) others should decide for the residents (or) the residents should not be allowed.

WORK/ DAY ACTIVITY

24. Can the residents leave their job/ day activity if they want to, do no work and stay at home? Do the residents need to ask anyone? (would anyone try to stop the resident from leaving if they wanted to?

Option Set 1	**Option Set 2**
( ) yes the residents can leave if want to. They do not have to ask anyone else. ( ) The residents discuss with others and decide ( ) others decide (or) the residents are not allowed to leave	( ) the residents should be free to do whatever they want. ( ) The residents should discuss with others and decide. ( ) the staff or others should decide and the residents cannot decide

25. Can the residents be late home from work/day activities? Do they have to tell anyone first or ringup?

Option Set 1	**Option Set 2**
( ) The residents can come home whenever they like. The residents don't have to tell anyone first or ring up. ( ) The residents can be late if they want, but they are suppose to ask or tell someone first or ring up. ( ) others decide (or) the residents are not allowed to be late (or) the residents have no opportunity to stop off after work & get back home late because their work place is attached to the group home.	( ) the residents should be allowed to come home whenever they like. They don't have to tell anyone first or ring up. ( ) the residents can come late, but they should tell someone first or ring up. ( ) others decide. (or) the residents should not be allowed to be late.

26. What happens if the residents want to take a day off work / day activity when they are not sick? Do they need to ask anyone first?

Option Set 1	**Option Set 2**
( ) It is the residents decision.(they might loose a day's pay) ( ) The residents decide with help. They ask others. (e.g. staff or family) first. ( ) others decide-the residents have no real say. (or) the residents are not allowed. They have to go to work/activity.	( ) it should be the resident's decision. ( ) The residents should decide with help. ( ) others should decide for the residents.

OVERALL CHOICE

27. Overall wouid you say that the resident's life is free so you they can choose what they want? All the time?

Option Set 1
( ) yes definitely
( ) yes, most of the time. Sometimes it's planned for the residents
( ) No. The residents often cannot do what they want.